

Health Commons/ Smart Patient Program

Final Report for Metro South Health

Kathryn Alexander

Research support

Lizzie O'Keefe

Contributors

Belinda Noakes, Stephen Alexander & Savita Sandu

We need to move from
What's the matter medicine to
What matters to you medicine.

Maureen Bisognano, President and CEO, IHI

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I don't know the right treatments or how
to ask the right questions
at the right time.

I have to rely on others and
what they feel which may not match
what I feel. I am not helped
in the way I need to be helped.

Foreword

Health sector challenges, solutions and the Smart Patient.

Belinda Noakes & Stephen Alexander

Public health sectors around the world report that new money for healthcare becomes harder to find each year. In the future, health providers must fund service delivery through innovation and prevention.

Health Sector Challenges

Public and private healthcare providers face significant challenges, all exacerbated by pressure on the health sector from health risks and economic stress related to COVID-19:

- Obtaining healthcare is fast becoming unaffordable for many individuals, with gap payments increasing each year. A 2018 Queensland study of more than 452 patients with one of the five most common cancers found the median out-of-pocket costs were highest for breast cancer patients (\$1,165 to \$7,459) and prostate cancer patients (\$971 to \$8,431). A research letter published by the Medical Journal of Australia in June 2018 found that cancer patients were paying up to \$22,000 in out-of-pocket expenses due to high medical fees.
- Chronic disease continues to rise. The WHO reports that noncommunicable diseases (NCDs) are collectively responsible for almost 70% of all deaths worldwide. According to the Australian Institute of Health & Welfare (AIHW) in 2017-18 47% of Australians had at least one chronic disease, 20% had two or more chronic conditions and chronic disease accounted for 50% of hospital admissions. Rates are up to 1.5 times higher in lower socioeconomic regions.
- Due partly to the impact of chronic diseases, providing healthcare is increasingly unaffordable for the public sector. Public health sectors around the world report that new money for healthcare becomes harder to find each year. In the future, health providers must fund service delivery through innovation and prevention.
- Social media and technology giants see health as a market ripe for exploitation and are new entrants to the sector. Large consumer-focused companies are moving quickly to leverage their existing customer relationships, gather personal health data and provide innovative new services. For example, in 2020 Amazon announced:
 - a wearable personal fitness tracker (Amazon Halo)
 - a partnership with Cerner to let Halo users feed data into their electronic health record
 - the Amazon Care service for employees, providing remote clinical consultations and prescription delivery (widely seen as a pilot for a broader consumer service)
 - Amazon Pharmacy, which lets people order medication from Amazon's retail website and mobile application, offering discounts up to 80% off competitor pricing
 - Amazon HealthLake, a cloud solution which enables healthcare providers, health insurance companies and pharmaceutical companies to store, transform, query, and analyse health data at petabyte scale.

Health Sector Solutions

The WHO argues the socioeconomic costs associated with NCDs make the prevention and control of these diseases a major development imperative for the 21st century and identifies four major risk factors — tobacco use, physical inactivity, the harmful use of alcohol and unhealthy diets — as primary drivers of the rise in NCDs. The British Medical Journal published a paper in 2020 noting that in the face of the global epidemic of diet-related chronic disease, there is increased experimentation with the use of “food is medicine” interventions to prevent, manage, and treat illness. The paper argues that scaled integration of emerging nutrition interventions into healthcare will require significant investment in rigorous research to test different approaches and address knowledge gaps.

In 2015, the AIHW reported that 38% of the burden of disease could have been prevented by reducing the exposure to modifiable risk factors contributing to the most burden: tobacco use, overweight and obesity, dietary risks, high blood pressure and high blood plasma glucose (including diabetes). The AIHW findings further strengthen the proposition that, while not a magic pill to fix all the health system’s ailments, supporting lifestyle change is a critical strategy for improving public health and reducing the burden on the health system.

Sir Muir Gray is a leading proponent of health system reform in the UK who argues that patients will drive innovation and change in the third (digital) healthcare revolution, rather than clinicians or administrators. Sir Muir Gray notes that a shift towards patient value is the only solution for healthcare, because consumer demand will drive change as a direct consequence of increased access via smartphones to digital information about health solutions.

Results to date from the Smart Patient research support the notion that patients who have a chronic disease and are willing and able to participate in their own health journey can help substantially reduce the burden on the health system.

As the health system shifts towards a “hospital without walls” model and delivers personalised treatment to patients in the community it must develop the capacity to collect data, generate knowledge of what works and adapt treatment strategies based on proven best practices.

As the health system shifts towards a “hospital without walls” model and delivers personalised treatment to patients in the community it must develop the capacity to collect data, generate knowledge of what works and adapt treatment strategies based on proven best practices. To enable the kind of value-driven reform Sir Muir Gray advocates and meet the WHO’s challenge to effectively prevent (and in some cases reverse) chronic disease we will need to:

- know what works for different patients in different circumstances
- understand the impact of what works for patients in light of their specific circumstances, and
- gather hard evidence about the efficacy of specific solutions and their value in terms of improving patient’s lives.

Smart Patient Context

The Expert Patient program (delivered through the UK’s NHS) delivered a peer led, self-care support program in 2007 for people living with a long-term condition. The initiative demonstrated that patients suffering from a chronic condition could improve their experience and were better able to deal with the impact of long-term illness. ¹

Although Expert Patient showed that lifestyle does have a positive impact on health, it did not provide sufficient evidence to prove the value of lifestyle change or the positive impact community resources and other health interventions could have on people’s health and well-being. In 2019 Steven Miles, then Health Minister for Queensland, approved funding for Smart Patient: a year-long research project that would build on the outcomes of the NHS Expert Patient program as well as work completed in 2015 to assess the impact of chronic disease in the Logan and Redlands regions.

The research project collects 30 data sets from people aged between 20 to 50+ years who suffer from one or more chronic conditions and wish to exercise self-responsibility to get to a better place health-wise than where they are now or where they are currently heading. The data sets enable analytics on the person’s experience of their condition and circumstances, their key aspirations, the main barriers and inhibitors, the most important requirements for generating confidence and motivation, as well as the value of any resources that helped people achieve their aspirational end point.

What does Smart Patient show?

This interim report provides an update on the ongoing year-long monitoring of the original cohort that received training on how to better manage their healthcare journey. Results to date from the Smart Patient research support the notion that patients who have a chronic disease and are willing and able to participate in their own health journey can help substantially reduce the burden on the health system.

Data included in this interim report provides insight into patient value by measuring and validating each individ-

ual’s experience and the change in their experience over time. Preliminary results reveal, for the very first time, what solutions the patients experience as most valuable. Value means any specific solution’s ability to solve the problems that generate the most friction and pain for a particular patient, within the context of their condition(s) and life circumstances.

Furthermore, the research identifies what barriers most commonly inhibit patients from addressing these problems and nominates five specific principles that affect a health consumer’s capacity and willingness to become proactive. These principles have important implications for the design of future interventions intended to improve population health and healthcare affordability by managing and preventing chronic disease.

The final Smart Patient report is due in March 2021 and will include comprehensive findings, conclusions and recommendations on a number of broader topics including:

- unpacking the collective value experience of the research cohort
- examination of where crowdsourced data fits in a “hospital without walls” scenario, including the potential for digital asset generation, monetisation of data for the common good and new capital creation
- an assessment of the potential value impact for businesses, government and the local economy of broader adoption of the Health Commons apps, learning platform and community capacity program within the MSH ecosystem (ie. improving regional resilience)
- recommendations for a Stage 2 trial using apps, online learning and community support capacity development

Preliminary observations and results are already being built into the first Health Commons app and online learning environment, to be trialled in Australia and the UK during 2021.

[1. https://www.mja.com.au/journal/2008/189/10/unit-ed-kingdom-expert-patients-programme-results-and-implications-national](https://www.mja.com.au/journal/2008/189/10/unit-ed-kingdom-expert-patients-programme-results-and-implications-national)

The Research Program

What does it take for a patient to become proactive in their world?

Despite the growing pandemic of chronic disease, the burden of disability, the healthy years lost, and the risk of premature death, we still struggle to sufficiently address the known modifiable risk factors, such as stress, smoking, physical inactivity, poor nutrition and the harmful use of alcohol, to make any meaningful impact on the burden of disease.

With the financial cost of chronic health now outstripping many governments' capacity to pay, we are now seeing these increased costs being passed to the health consumer. However, spreading the cost of health across the community will have little to no impact on the non-affordability issues or the rise in chronic disease, both for government and health consumers alike.

If the modifiable risk factors are a root cause then patient proactivity to reduce these should alleviate this burden dramatically, especially within the next generations.

https://www.aihw.gov.au/getmedia/8f7bd3d6-9e69-40c1-b7a8-40dca09a13bf/4_2-chronic-disease.pdf.aspx

https://www.who.int/nutrition/topics/1_introduction/en/

Interim report - post training

The problem for the patient is not the illness, but how they're going to deal with it.

This grounded research project was to discover what conditions favour proactivity in patients managing their chronic condition and what resources, or combination of, provided the most value to their journey. The program measured the experience of the impact of their condition and circumstances on their life, recorded any reduction in impact over the course of the program, and the types of resources that were of most value.

The study enrolled 30 participants with a chronic condition who wanted to be in a better place, health-wise. They undertook a 10 week training and then were monitored at 3 monthly intervals for one year as we measured the value impact of any resource upon their experience, including health outcomes.

This interim report focuses on the findings after the initial 10 week training where the intention was to discover what a person requires to become proactive and "adopt responsible behaviours" that would support their health journey. The team discovered that a sense of meaning for the individual's journey, the capacity to see the possibilities and the willingness to implement solutions that would lead to incremental change were all key drivers. In addition, the team found that the ability to predict the probability or odds of a chosen plan working for people (which was offered as part of the supporting training program) increased confidence and motivation. The study did not exclude the social context within which change occurs and many participants indicated that *dealing with*

the peripheral issues helps you put yourself first as a focus. All participants saw their health issues as subsidiary to any social circumstances they were battling.

Participants went on a facilitated journey over a 10 week period, where they received support to develop a concrete plan that met their personal criteria. Each person's journey had meaning (aspiration) and purpose (meeting set criteria for measuring the experience before and after the journey). They each made decisions against those criteria choosing solutions were most likely to work for them. Scoring was undertaken during and after the training to measure the impact on experience.

After the initial 10 weeks training, participants reported increased motivation and confidence based upon their achievements, improved experience and better health outcomes.

The analytics to be covered at the end of the program:

- what combinations of resources (including both treatments and social requirements) were the most valuable for individuals;
- what are the key drivers for change;
- what are the key obstacles for change;
- what empowers a person to make change;
- what makes people reluctant to change and stands in the way of pro-activity;
- what are the implications of the outcomes on the person's circumstances and health conditions;
- the potential implications for outcomes for other people dealing with similar conditions.

Training of the Health Commons/Smart Patient participatory methodology, analytics of what worked for each participant and collective value experience, printed surveys, workbook, teaching videos and graphics. In addition, reporting to Metro South of conclusions of what worked in terms of the value impact of any resource upon the individual regarding their experience.

The Scoring

Measuring the intensity of the experience

The model focuses on capturing and scoring the intensity of the experience from the individual's perspective from a range of influences that impact the person's journey, and then scoring any reduction in that impact as the journey progresses.

The categories for scoring included:

- five key determinants for progress: confidence, motivation, general health, stress and contentment;
- the barriers (circumstances or personal);
- relationships (unmet needs); and
- health parameters (objective and subjective symptoms).

In order to get consistent and meaningful scoring we used the scoring template to help describe and score the intensity of the experience on the journey, relating each emoticon to how much friction or ease the person was experiencing as a consequence of their problem at each way point. This ensured that we were not measuring the circumstances but the impact of experience of those circumstances. With each problem identified, they could select and score its level of intensity from the template, and then describe how it made them feel.

Solutions were selected on the basis of their capacity to reduce the intensity of that experience. Single solutions that could reduce pain from many competing influences (hot spots) would become core solutions and take the person the furthest. Solutions, therefore, were not limited to things you do or implement but novel ways of approaching and dealing with the various scenarios that cause friction and negatively impact the journey, and they

would be tagged to that experience. Each individual would initiate their own unique solution-set to make their journey a possibility. Solutions arrived at through this autonomous, reflective process tended to be strength-based and therefore had a greater chance of being implemented and working.

At the outset three scorings of the intensity for each impact were taken:

- As is: the intensity as it is now
- Needs to be: where it needs to be to cope better;
- To Be: what they would like it to be, all things being equal

The Needs to be score was the first way point and pulls out the solutions. Participants were encouraged to view this as the first step, or the amount of reduction in impact they would need to see that would encourage them and get the ball rolling, and to describe *What would help me get here?* If the Needs to be score was too close to the To Be score, finding solutions to start the journey may be overlooked, and there was a danger that the journey may not start.

At the end of the training the first set of post course progress scores were taken for each impact within each category. Again, we captured the meaningful insight for any change in score and recorded what had helped.

The closer a root cause description is to the solution, the more useful it is for working out your strategy.

Scoring Template

	10 Extremely hard/distressing: it's the worst it could get I'm stuck; there's no way forward It's impossible	As is: I get anxious and extremely stressed. I shut down and isolate myself. I have little joy and my heart feels dead. I have many responsibilities for others.
	9 It's very hard/distressing It's not budging; nothing is working I can't see any possibilities	
	8 It's hard/uncomfortable There's not enough movement Any possibilities are a long way away	
	7 It's just about tolerable Movement is slow but I can just about cope I can't get a handle on what's possible yet	
	6 It's becoming manageable Movement is slow but I can live with it It should be possible	Needs to be: I need to learn how to relax, manage my mental health and anger so I have circuit point.
	5 It's manageable Movement is slow but I can work with it I'm seeing some possibilities	
	4 It's getting easier I'm moving forward and feeling encouraged I'm experiencing positive change	
	3 It's much easier I'm moving forward and experiencing the benefit I'm feeling new possibilities	
	2 Life's good Things are going my way It's all possible	To be: To be able to relax in my own space would give my life pleasure and provide happiness. I will be able to sleep without assistance.
	1 Life's very good; it's A-Okay We're in the flow New possibilities are on the horizon	

“ I get anxious and extremely stressed. I shut down and isolate myself. I have little joy and my heart feels dead. I have many responsibilities for others. ”

The Proactive Principles

The capacity and willingness of a health consumer to become proactive may be negatively impacted by their circumstances, which includes both the social context and general health, their immediate environment, their level of trust of self, others and information, and their interpretation and understanding of their health journey.

Many health consumers feel lost, they don't know what to ask and they don't know what could work for them, which undermines both confidence and motivation. They struggle with information overload and may feel overwhelmed at the enormity of what's expected of them. In addition, people can feel trapped by their circumstances as the reality of change appears slim.

Becoming proactive against this background is a tough call, particularly because any program that makes a measurable difference will need to be long-term and sustainable and the outcome has to be of sufficient magnitude to make a meaningful difference. Adoption of lifestyle changes that are driven by fads are unlikely to work long-term, so a fundamental requirement is a shift in perspective where the journey is driven by what is meaningful to that person, progress is measured against improvement in experience and solutions that are aligned to the experience became a means to an end, rather than the end itself.

Although circumstances that negatively impact a person's journey may not change significantly, what can change is how someone experiences those circumstances. Although the two are often co-dependent we all know that changing our circumstances is not necessarily synonymous with a better experience. A successful journey is one that is worthwhile where its "worth" is tagged to *what's in it for me?*

Proactive principles include

Meaning

Orientate the journey around purpose, reason and meaning where *what I want to achieve and what this would mean to me* becomes the key driver. Through measuring the impact of the experience, rather than the impact of the circumstances - *what does this mean to me and how does it make me feel* - and choosing solutions to specifically reduce the intensity of that experience brings more meaning to the journey, greater motivation and makes it worthwhile. It answers the central question *Why should I bother?* Through the research we can begin to appreciate how the experience drives the journey and the change in experience is the reward that makes the journey a probability.

Self-reflection

Holding space to look - unpacking real life scenarios provides an opportunity to view these through a wider lens and focus attention on the experience/problem that may be common to two or more scenarios. Grounding the experience in this way gives greater capacity to join the dots and broadens the scope of solutions through factoring in both the experience *what will this mean to me* and the circumstances *how will it practically improve my circumstances*.

Imagination

Creative solutions for incremental change - having an aspiration and seeing its possibility is a key pre-requisite for taking action to realise the journey. Through focusing on the first step to start the ball rolling, solutions that were within grasp and strength-based were more likely to work and offer immediate reward. Motivation, which is often scored as a measure of intensity of the need, can be undermined if the stakes are too high or the solutions too difficult. Those that were prepared to take incremental steps, using solutions that were focused on reducing the intensity of the impact of the experience, were able to make meaningful progress.

Several participants commented on the value of shifting from the all or nothing attitude, to one that was focused on incremental change. Solutions that support incremental change can dramatically unblock the journey, enabling the person to see and realise the possibilities, both of which motivate the journey and, in some cases, modify/enhance the aspiration and change the direction.

Knowing

Seeking confirmation not explanation - although greater health literacy can support health consumer choices it is not a strong motivator for change nor does it, by itself, bring the person to a point of readiness, or even trust. Most complained of information overload and the struggle to make sense of the information within the context of their case. As one participant put it *you have to know what you need before you can ask for what you need*.

Through seeking confirmation not explanation, greater confidence is generated in the capacity to make decisions on products, treatments or pathways. Learning how to pre-qualify what's on offer and measure its value against key reference points (what do I need to achieve and why,

and within what time-frame) enables the person to ask the obvious and rapidly determine the value. Treatments that offer the most value will be those that deliver most meaning to the journey, while being able to pre-qualify the odds of a chosen plan working for them increases confidence and becomes a strong motivation for change.

Willingness

Overcoming resistance to change - means that change has to be worthwhile, which requires having an aspiration and a willingness to find solutions. Solutions that are aligned with the experience and generated through personal choice (self-determined) are more likely to be implemented than those arrived at through coercion or expectation. When there is unwillingness to find solutions then barriers became no more than excuses, which lock the journey.

Furthermore, solutions that address the individual preconditions that need to be met before the benefit of anything else can be realised will increase the probability and willingness to undertake the journey.

Preconditions indicate the type of support or environment required in order to make change, which may include space, order, understanding, connection and communication. Solutions that deliver this are pivotal to the journey. Participants who were able to find solutions that supported their preconditions were able to start making meaningful progress prior to the end of the course. Those participants who were in an environment that didn't support change struggled to get meaningful outcomes. Invariably, kind support from others was sufficient to meet the preconditions, and the practical solutions selected provided the means.

Principle 1

Meaning

“ We need to move from *What’s the matter* medicine to *What matters to you* medicine. ”
Maureen Bisognano, President and CEO, IHI

We observed that most people did not mind living with a chronic condition if it could be managed and did not impact their lives beyond a specific threshold. The impetus for becoming proactive was driven by the experience that arose as a consequence of those health conditions, such as fear for future health security, non-affordability, frustration, despair, isolation, lack of independence, being trapped, unable to cope and an inability to achieve what one needed to.

Motivation to become proactive is driven by these experiences as we rarely do things for the sake of it, especially when it comes to making lifestyle changes which often generate additional friction, so in order to make any sacrifices the reward needs to be worthwhile. Solutions, therefore, need to reduce the burden of the specific circumstances and improve the experience.

Our participants came with a wide range of conditions and circumstances. The task was to unpack the starting point *Where am I now and what does this mean to me?* so that they could link problems to experience. By grounding the experience in this way it becomes possible to choose solutions that meet both criteria.

The task was to take a complex set of events and experiences and reduce it to a coherent and logical framework against which each participant could align solutions and monitor their progress.

We measured the starting point experience in three key areas, general health capacity, stress and contentment, and pulled to the surface any theme or common experience in order to determine what solution could meet that need. In case 22, difficulty in coping was a recurrent theme, where the solution for that person was to ask for help and support, which would also generate the environment within which change could occur.

A similar exercise was undertaken with each of the barriers, to define the problem, how it impacted the journey and what this meant to them, in order to discover the needs and the solutions that would reduce the pain/improve the experience and make the journey possible.

The journey moves from a place of pain and friction to a state of greater harmony. By matching the experience with tangible achievements *Achieving.....[this], would give me.....[improved experience]* gave focus and direction where meaning was the key criterion for determining which solutions could have the greatest impact on the journey.

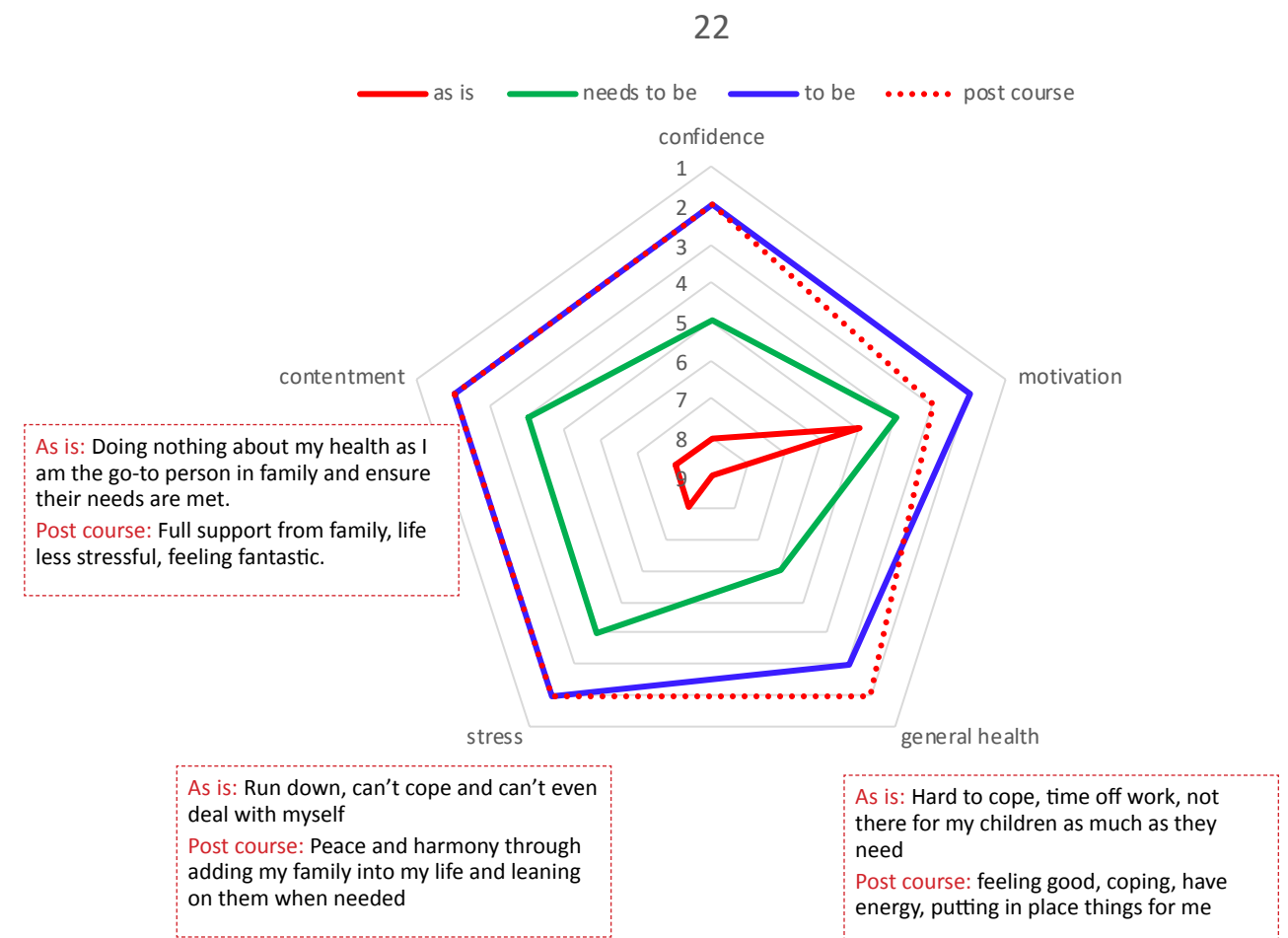
Giving meaning to the journey reminds us and others of why we’re doing what we’re doing and helps keep us on track and motivated. Being rewarded through improved experience provides sufficient motivation to keep moving forward. Common themes around unmet needs often lead to solutions that are simple and elegant, and have the most impact.

“ It’s helped me focus on things I have control over instead of being overwhelmed by the enormity of the situation I was in. It’s meant the start of my journey, getting my life back so that I can live again. ”

Female
39 years
Full time employment
Dependents: 2 small children
Medical condition: Lupus, Blood clots, High Cholesterol, Anaemia, Reflux

Solutions
Family support, asking for help / accepting help, saying No, leaving work at work, prioritising and taking time for self, cooking routine, diet change/healthy snack options, better sleep, natural remedy for reflux (plus diet changes)

Case 22: Overall Progress Radar Map



“ I feel run down and find it hard to cope. I have to take time off work and I am not there for my children as much as they need. I am doing nothing about my health as I am the go-to person in my family and ensure that their needs are met first. I have no confidence in putting in place a strategy of what’s best for me and will work. ”

Principle 2

Self-reflection

“ It has given me space to sit with my frustrations and feelings, and then allowed me to look at my health and life problems from a wider lens. I have been able to make incremental choices and changes by letting go of an ‘all or none’ mentality and instead focusing on what are the options available to me, and how they fit with my priorities. ”

Self-reflection or holding space to look at our various scenarios, gave an opportunity to re-evaluate, to dig beneath the surface and look at the reasons as to why we may be where we are at, and the types of barriers that stand in the way. Many participants were locked in vicious cycles, where *I’ve tried before and everything has failed or I don’t know how I could do it differently or what would work for me.*

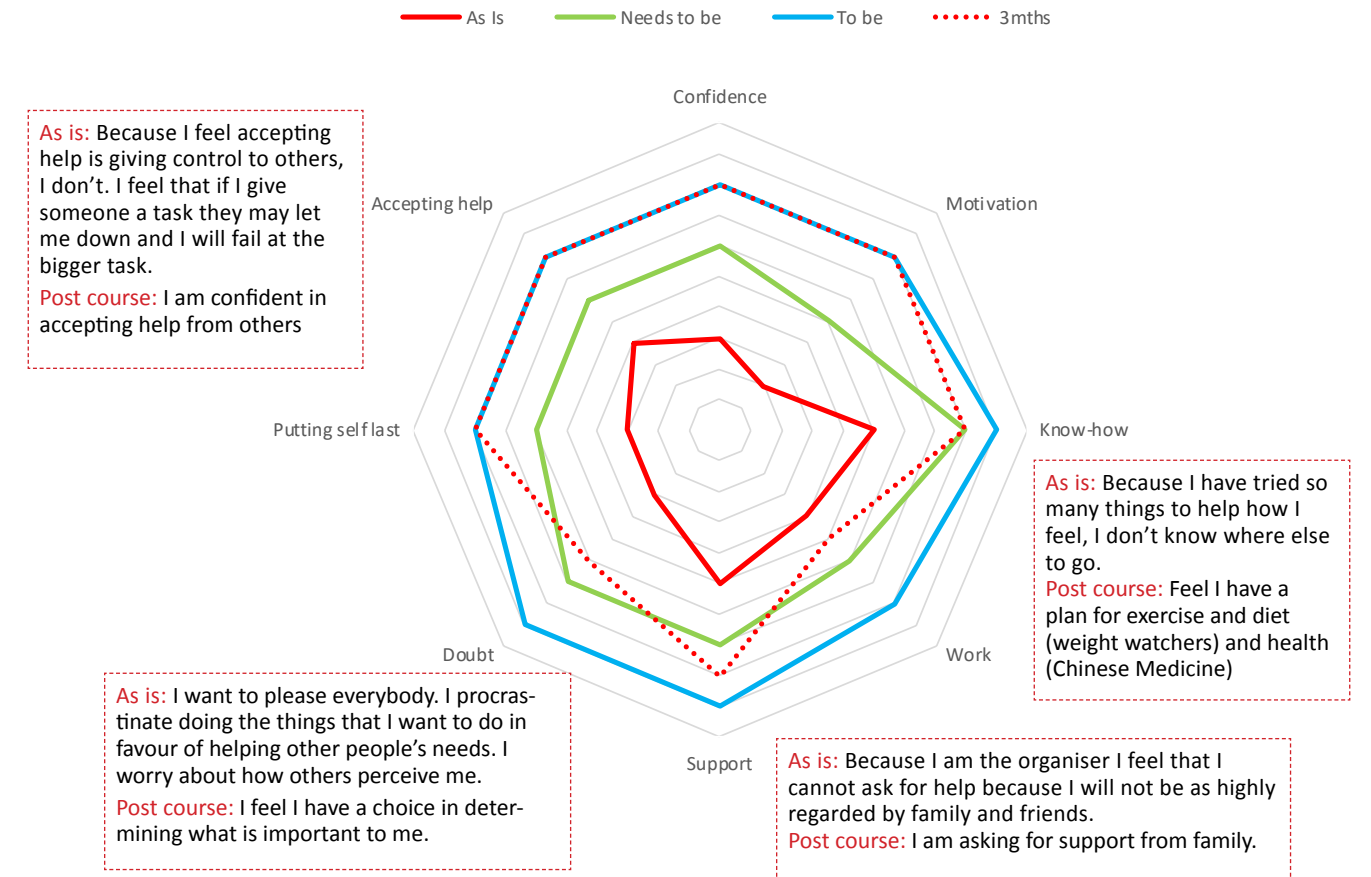
We observed that self-reflection seemed to initiate a shift in perspective, particularly with the realisation that one was often one’s own worst enemy. In an earlier training

that we ran for a small group in the Metro South region, we learned that motivation for change was undermined more by personal criteria, or self-imposed barriers, which included being committed/time poor, having self-doubt, inability to accept or ask for help, prioritise or put oneself first, or to say No.

From this grounded research the barriers list evolved to encompass both social circumstances (I would if I could), such as affordability, accessibility, work, safety, eligibility, cultural issues, and our personal criteria (I am my own worst enemy).

PERSONAL CRITERIA	Percentage of group
<i>I am my own worst enemy</i>	
Over-committed/time-poor I choose to take on too many commitments/responsibilities (work, study, social, volunteer work or family); I have difficulty in saying No; I find it difficult to prioritize my time.	35%
Doubt Efforts may be undermined by: uncertainty; fear of failure; nothing’s ever worked before; negative self-talk; pressure from expectations; being easily distracted/procrastination; may not be able to stick with program; may not be able to change my habits/way of doing things/lifestyle/give up my addictions; I would if I thought it could work.	80%
Putting self-last I don’t put myself first &/or prioritize my health or needs; I tend to put myself last/put others first; I feel everything is always up to me	65%
Accepting help I find it difficult to ask for help; I am unwilling to accept help even if I need it; maintaining my independence is an issue for me	60%

Case 14: Barriers Radar Map



This discovery obviously shifts the root cause of a problem to our own behaviour patterns which influences the choice in solutions that could work, and the direction of the journey. The all or nothing approach where one focuses only on the end point, often misses the mark if the solution cannot fix the root cause. If the barrier is *I haven't got time to look after myself* we may find that for one person the root cause is an inability to say No to others, but for another it may be procrastination through choosing to do others things instead.

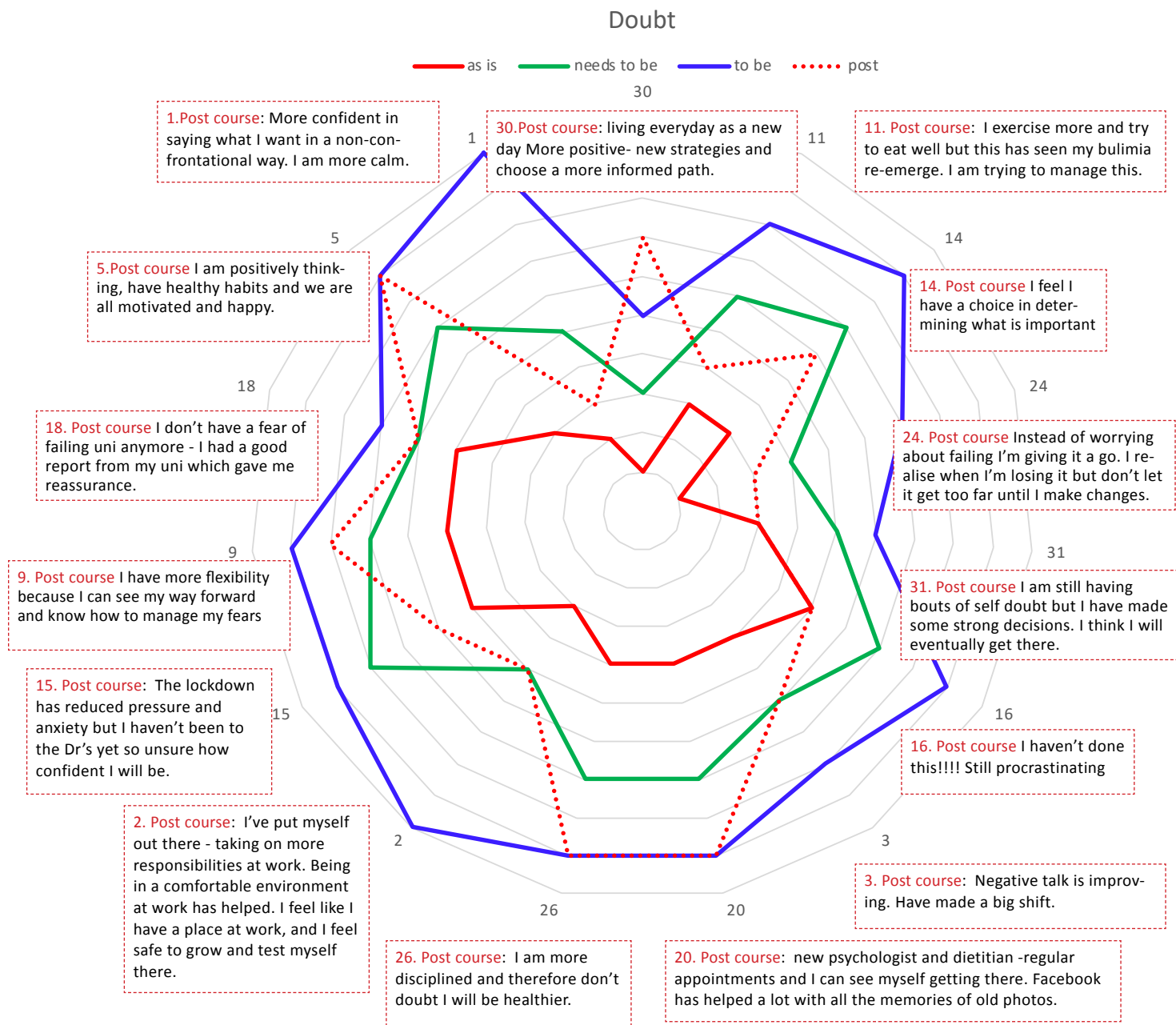
As we reflected on each scenario participants saw patterns emerge where a root cause may become dominant and reappear across many scenarios. With this appreciation, it became obvious that solutions that addressed root causes would stand a greater chance of working and take them the furthest.

Solutions that addressed the fundamental causes enabled the journey and altered the experience of the journey, whereas other more practical solutions provided the means.

Case 14 is a good example in point. At the outset of the program she said *I don't know where to start and I don't know what I am going to do differently.* Doubt was a barrier and she was able to identify why she doubted the journey could be successful: *I want to please everybody; I procrastinate doing the things that I want to do in favour of helping other people's needs. I worry about how others perceive me.*

The end point for doubt then became *To feel free and at ease to choose the things that are important to me,* and the first way point (needs to be) was *To prioritise and be able to consider, and possibly say No.*

Group Radar Map: Doubt



“ It made me look deeper into the core of the problem, not just surface and gave me a more comprehensive understanding. It has given me more confidence that it is doable. ”

Group Doubt: AS IS, NEEDS TO BE and TO BE statements

	DOUBT: AS IS (PRE-COURSE)	DOUBT: NEEDS TO BE & TO BE
30	I have been told that there's no hope for the future and I just have to do what I can do.	Need to get a glimpse of some possibility; getting some weight loss; get a diet and count calories. To be able to feel more confident that it's possible, I can do it and things are changing.
11	Difficult to maintain energy my motivation waivers and I get to an exhausted "fuck it" point.	Get a comprehensive meal plan, be patient with low impact exercise plan I would trust myself to find more sustainable gentle & incremental goals.
14	I want to please everybody; I procrastinate doing things that I want to do in favour of helping other people. I worry about how others perceive me.	To prioritise and be able to consider and possibly say no. To feel free and at ease to choose the things that are important to me
24	Because I doubt myself it means I am not achieving any of the things I would like to	Prioritise my mental health. Positive self talk. Do things I enjoy Being able to achieve the best possible outcomes in activities that I do would make me feel more positive.
31	I am down on myself all the time - can't be bothered to look after myself - I gave up smoking for 3 months then started again - it all gets too hard.	Find a plan to give up smoking and lose weight Being kind to myself would give me confidence that I could live my best self.
16	I tend to procrastinate exercising even though I know it is important mainly due to time poor and tiredness after work.	To start with exercising 3 times a week to leave work by 4:30pm or to wake up earlier to do the exercise. Achieving my goals with better health would make me feel confident.
3	Fear of failure and strong negative talk	Acknowledge my success instead of only seeing my failures Better self belief in being able to achieve my current issues & future issues
20	Because I can't see myself at that point of being 65kg it makes me feel if I don't get to it that I have failed.	Not to be in limbo, I need to phone and get my new psychologist to make an appointment and to get more enjoyment as I am doing the journey. That I can have a full life with my husband.
26	Discipline to do what it takes is hard but partly due to low energy.	Find a new normal of eating & being healthy. Have more energy so it doesn't feel like a chore and can do things and still feel in balance. Get on treadmill instead of comfort eating. Balance, peace and harmony.
2	My doubt stops me from moving forward and I feel like I'm not good enough.	Put myself out there and take more responsibilities with support at work With confidence and a greater sense of self - then I would move forward.
15	Listening to my anxiety and doubting myself with Drs. I have no hope of motivation.	Learning tools to help with anxiety. To have the confidence to ask the right questions and stand up for myself.
9	Feel doubtful of being successful because I can't even deal with my own problems. I am frightened of being seen as a failure by others.	Gaining support from close friends to have a feeling that I'm still loved in spite of losing some of my achievements. Identify what I most need and not grab at lots of things. Having better resilience of considering what I am and look like with flexibility with what I have. To be able to let things go if they don't suit me
18	Having a fear of failure with uni studies; not being able to find work; I am not confident.	find uni mentor or seek tutors to assist with assignment; visiting job hot spots and putting in my resume With all the support I need from family, friends, mentors and tutors would give me confidence to be successful in seeking and getting a job
5	I doubt that I will stick to a plan, struggle to start thing if I can't continue the work.	I would have better sense of happiness if I can make a commitment to start in my mind and feel in my heart that I can do this. Prepare a plan that makes life easier and is healthy. Positive thinking with good healthy lifestyle habits.
1	I don't trust myself to be capable of making permanent change. I have tried so many times, I doubt that I have the will power to sustain	Small steps and feeling of success. I would be more confident and feel proud of my success.

Imagination

“ A lack of imagination is a poor excuse for under-achievement. ”

B. F. Balcombe

Through the process of self-reflection and adding meaning to the journey in terms of *where would I like to be/what would I like to be experiencing* it was possible to create three overarching aspirational end point statements (To Be statements) at the first session by looking at and scoring the impact on their lives of their general capacity (health), stress and contentment. Three To Be statements were created in relation to where they were now and these became the journey lighthouse. These statements appeared in the clouds in each of the trees (barriers, relationships and symptoms) as a reminder that any solution had to not only fix a problem or address a root cause, but also take them in the right direction.

Imagination is the capacity to see possibilities after having looked at the problem through self-reflection. Imagining where you would like to be in relation to where you are now and then to describe the impact of that experience gives meaning to the journey.

Imagining an aspirational end point was difficult for those who were living in an environment that didn't support change or where there was a lot of friction as they could not see how they could move from where they were now to something better. Participants were encouraged not to reach for the stars, but to imagine realistic or reasonable aspirations that would bring significant meaning to their lives.

“ It gave me the ability to be brave. It gave me clarity and confidence to break old habits and create something different to help me that is mentally and physically healthy. The bit sized piece that the course has provided has enabled me to understand and put in place my strategy that has really worked for me. ”

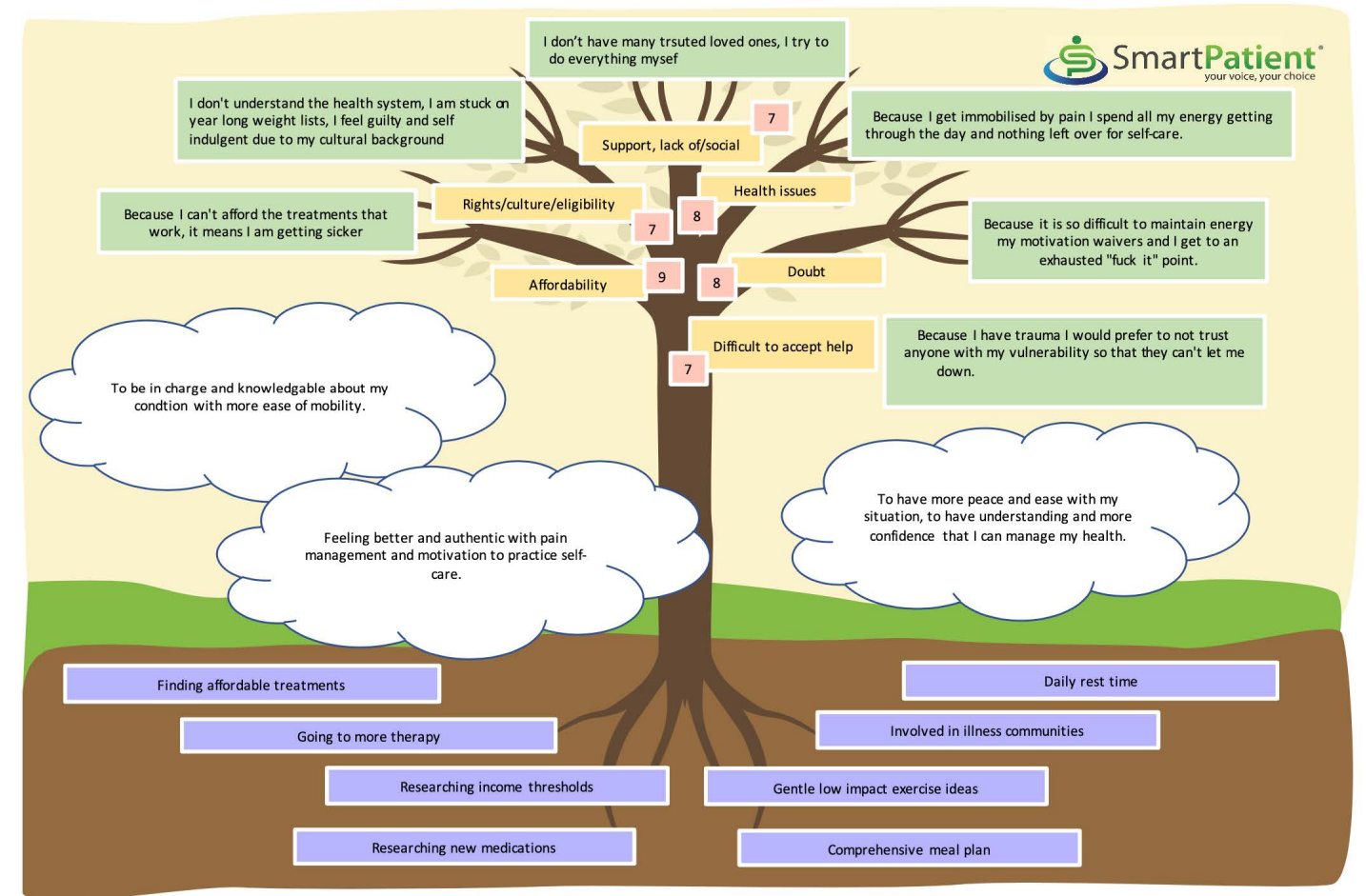
There were between three and eight To Be statements that had to be crafted for each of the trees where the To Be statements were contextual to each problem or impact and to the aspirational end point statements.

The greatest difficulty for all was imagining the Needs to Be statement, or the first step that would get the ball rolling and reduce some of the impact or improve the experience sufficiently to help them feel that they were heading in the right direction and motivate them to keep moving forward on the basis that it was both do-able and worthwhile.

This meant shedding the all or nothing approach and having imagination to look at possible solutions that would give a lift to the first step on the ladder, support incremental change, reduce the pressure and give more hope.

By approaching the Needs To Be from *what would help me feel less[stressed, frustrated, helpless] in this given situation* it was easier to see what was needed and where to ask for what was needed. As one participant said *You have to know what you need before you can ask for what you need.* When this is within the context of the scenario and its related end point, its full relevance is appreciated and one is able to measure the impact of the solution on the whole journey.

Case 11: Barriers Tree



“ The logic that I learned from [the course] works for me like a formula where I knew the answer and the light bulb went on. It changed my attitude in a very short time. I didn't expect to be able to change this behaviour so soon. Just being able to communicate with my doctor has been a very valuable lesson. I'm so grateful for this course and I have really learned how to cope and put in place a plan and have the motivation to follow through. The most important part of being able to get what you need is to be able to communicate what you need. It's been a really great journey. ”

Principle 4

Knowing

“The course provided valuable information in order for me to take control of my own health; it highlighted the need for me to be the primary decision maker for my health choices; my GP and other health professionals invest in treating the symptoms until there is a need for medical intervention.”

Although most patients had some health literacy, most were focused on their frustrations in dealing with the health system, and saw this as the main barrier to getting the treatment they needed to help them become well. They saw it was the responsibility of the health professional to know which included understanding the impact of their condition on their lives and factoring this in when making any recommendations.

Having a good working relationship with health team members and an easy to navigate system supported a desire to become proactive. The main feedback at the beginning of the training was that participants felt stuck, lost and had a lack of trust in the system.

Lack of trust: *I distrust where I GP is heading and I have reluctance to have prescription medicine. I don't want to manage my condition with medication.* [Case 26]

Each time I got to specialist they want to add a new diagnosis and new medications which means more side effects whilst trying to maintain my job. It makes me feel frustrated and more doomed. [Case 30]

Fear: *I'm worried that I might die and wouldn't be here for my kids. I'm worried that I have diabetes and I won't check in with my doctor.* [Case 5]

Why bother: *Because I smoke and I am overweight it means that my diabetes is not in remission. I am stressed most of the time when my son is at home and I miss my ex-partner which depresses me. So I basically think all the time 'why bother'.* [Case 31].

Not being heard

My condition is still up in the air and I am meeting specialist push back to my questions. It is therefore still difficult to get a treatment plan. [Case 11].

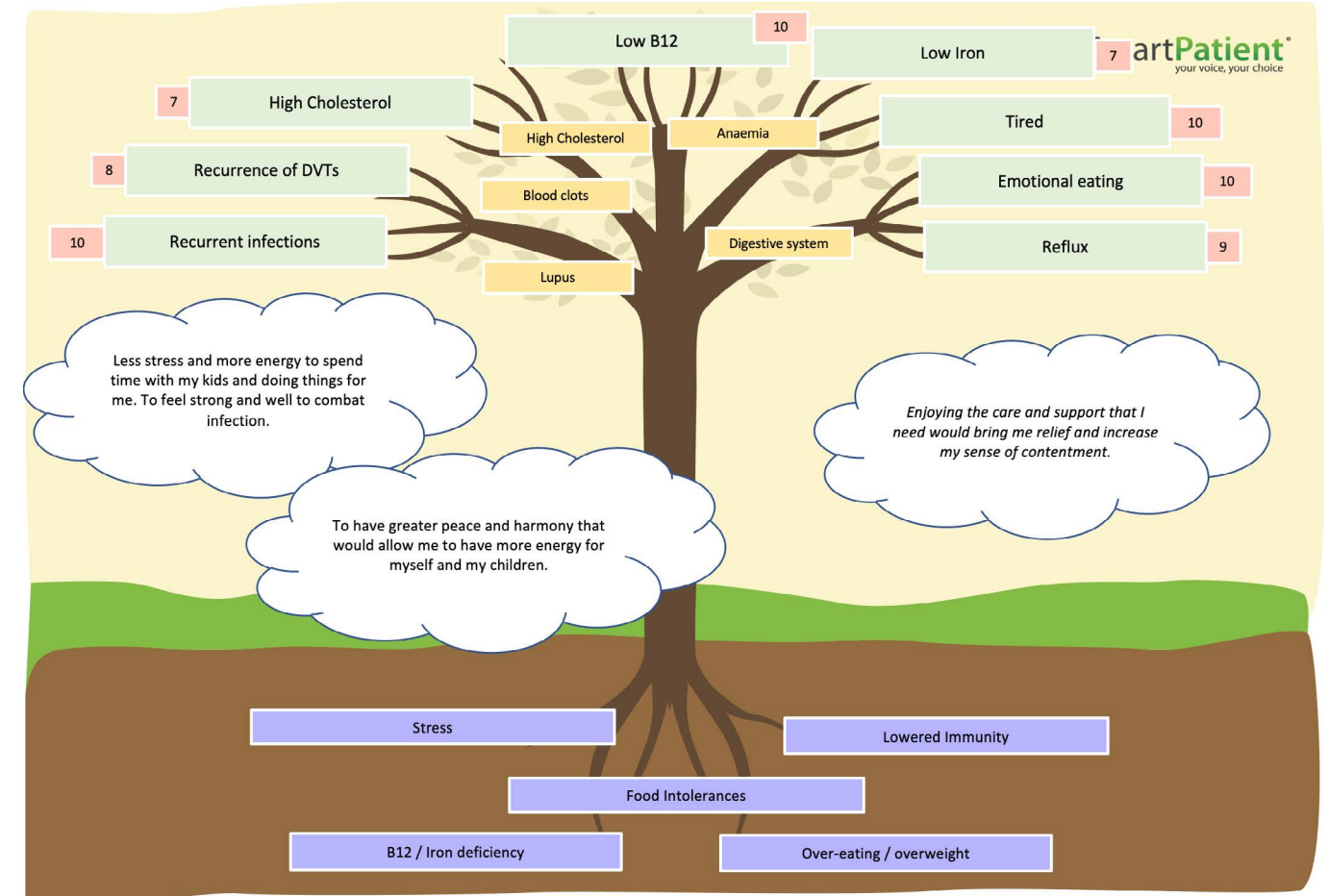
Everyone wants to explore different avenues as they have different opinions. Many give their opinion but they don't understand my condition or how it affects me. [Case 30]

Being given the run-around

I've had to move for the specialists I require; have also had to move hospital, I feel like I'm just being moved around. There is no central person to ensure that whatever's offered is suitable. I am now refusing treatments. [Case 30].

“I have made life changes because of this course - more involved in what I need medically and better able to understand and communicate with specialists when discussing medications and my preferences with good result; more positive about my diagnosis and being more interactive has given me a better outlook about my prognosis.”

Case 22: Symptoms Tree



Managing risk: starting point & default end point

It was clear that participants, although seeking information, this was primarily to confirm which treatment options would offer the best outcome for their individual case. The process of seeking confirmation rather than explanation requires a set of questions that are aligned with specific journey objectives, laid out by the patient in relation to key reference points:

- the starting point (*where am I now*);
- the default end point (*where am I currently heading, if I do nothing*);
- the goals (*what do I want fixing*); and
- the end point (*where would I like to medically end up*).

Most participants knew their diagnoses and the symptoms that belonged to each, but some were confused as to their medications and the purpose of these. Research focused on collecting the minimum required to complete their symptoms tree which showed the relationship between diagnoses, symptoms, causes, including lifestyle causes. We used www.patient.info to find the information which included the future health risks. Medications could then be tagged to specific risks. For research on medications we used www.drugs.com, again pulling out the bare minimum that would answer the questions for the treatment's end point:

- What does it do/how does it work;
- What future health risks does it mitigate;
- How long do I need to take it for; and
- What are the risks?

Lifestyle causes & risk factors survey

Diagnosis or organ system affected	Blood clots	Anaemia	Lupus	High Cholesterol	GORD
List of lifestyle causes, risks and exacerbating factors					
Stress			✓		✓
Poor diet (quality & quantity)		✓		✓	✓
Foods or food allergens (name these)					
Nutritional deficiencies (name these)		Fe, B12			
Overeating				✓	✓
Under-eating					
Over-exercising/inappropriate exercise					
Insufficient exercise	✓			✓	
Insufficient fluids					
Insufficient sleep or rest					
Hygiene/conditions favouring spread					
Alcohol					
Smoking					
Recreational drugs					
Injury (name type of)					
Infection (name this)					
Environmental allergens: these include dust, pollen, metals, medications, mould, latex etc.					
Add name of allergen					
Environmental chemicals/radiation: this includes in the home, outdoors or occupational					
Add source/type of chemical/radiation					
Medicines/procedures: include current medicines/procedures that are a risk for this diagnosis					
Nexium		✓	✓		
Conditions that I have: include any of your other conditions that could be a risk/root diagnosis for this diagnosis					
Lupus	✓				
Other: anything else you can think of that makes a condition worse, such as weather change etc.					
Add					

“ The course gave me a head start to see and focus. ”

Many already knew that there was a need to make lifestyle change and were able to more fully appreciate the impact that this could make after completing the *Lifestyle causes & risk factors survey* particularly when one risk factor impacted more than one condition. The main lifestyle risks were added to the roots of the tree reminding us of what solutions would offer the most value.

The symptoms were scored, not by their level of intensity but rather by the intensity of the experience on the person's life. That experience was then scored and described. These symptoms became the way points for measuring progress where any treatment must reduce the impact of that symptom in a meaningful way for it to be of value.

The Medical End Point

For many patients it is clear that *Doctor knows best* may no longer be a yardstick for measuring value. In order to

fill this void our participants needed to work out where they would like to realistically end up, medically. Having worked through their lifestyle causes and risks and how far down the default end point line they may be, they could then ask themselves how far they were prepared to go in order to improve their health, and how much they would need to rely on medical input. By completing the *Medical end point survey* for each diagnosis, each participant could come up with an in-principle end point statement for their overall outcome, medical dependency and future health risks. This formed a key reference point for aligning treatments to the journey, where those treatments which could take them in that direction would have more value than those going in the opposite direction, or those that could show no value at all.

Medical End Point Survey

Medical end point survey		My end point
Overall outcome	Heal all my conditions (no reliance on treatment)	
	Improve my general health (less reliance on treatment)	
	Preserve/stabilize my general health (hold my health where it is now, stop it going backwards)	
	Slow the progression/deterioration of my general health	
Quality of life	I only want to feel better (symptom relief only)	
Conventional medical dependency	Stay medical drug/treatment-free	
	Become medical drug/treatment free	
	Reduce my general medical drug/treatment dependency	
	Maintain, but not increase, my general medical drug/treatment dependency	
	I am open to increasing my general medical drug/treatment dependency, if required	
Future health risk mitigation	Reduce the future health risks I am concerned about associated with my conditions &/or their treatments.	
Name treatments with associated risks	Treatment	Health risk

Health Statement: the 60 second challenge

The health statement was pivotal in patient empowerment: to be able to convey what's wrong, what the risks are, what they want help with, what they would like to achieve and what criteria they may have. In this model knowing is focused around *What do I need to know that would bring greater certainty to my decision-making* and draws upon our natural inclination to work out the odds of whether something is fit for purpose or not. It is very easy to establish what a practitioner can and can't offer and for the patient to be able to understand their value within the context of their case and where they are heading.

Furthermore it was possible to work out the benefit / risk of a treatment based on these reference points using the Ready Reckoner Survey. Most participants found this relatively easy to fill in, even with the minimum amount of research.

“ I have support from colleagues and my GP as to assistance with medications and equipment for my condition and I feel I am being heard. My pharmacist researches my condition to assist where possible also. With new medication I manage this with minimal impact on my day. ”

My Health Statement

	My starting point	My end point	My criteria
Why state this	You need to give a concise account of your diagnosis and treatment to date to allow the practitioner to make a judgement on whether they feel they can help you.	You need to tell the practitioner where you want to get to and then match where the practitioner can take you against your own aspirations.	You need to measure how much synergy the practitioner and their treatments share with your value criteria (lifestyle, preferences and experience).
Statement Guide	<ul style="list-style-type: none"> I have been diagnosed with _____ and I have _____ (symptoms) I have had this condition for _____ (length of time) I have received medical treatment/am not on medication (indicate treatment, when you received it & length of time on treatment) I have been given a time frame (months/years) before my condition becomes serious. I have these known allergies/ inherited risks 	<ul style="list-style-type: none"> I would like to achieve _____ (healing, improved outcome/stabilise or slow progression) I would like to drug/product/ treatment dependency I would like to reduce these future health risk/s _____ associated with this condition I need help in addressing _____ (symptoms / root problems, causes) I would like to see improvement in _____ (within a specific time frame) 	<ul style="list-style-type: none"> Do you have <i>experience and success</i> in treating people with similar conditions to myself? (i.e. can you help me and how far can you take me?) Can you tell me <i>how long</i> the therapy/ treatment will last & can we <i>monitor the program</i>? What <i>lifestyle changes</i> may I need to make? Can you give any indication of the <i>costs involved</i>? Are you open to working with me if I use a <i>mix of conventional and alternative treatments</i>? Are you open to <i>collaboration or liaising with other practitioners</i>? Are you open to working with me if I <i>refuse any medical intervention</i>? My religion/culture <i>forbids specific treatments</i>, can you still work with me? I would <i>prefer not to.....</i> (do/eat/undertake), can you still work with me?
What the answers mean to me	<ul style="list-style-type: none"> If the practitioner can help me; What, specifically, the practitioner may be able to help me with; How far they can take me & when I can expect improvement; Whether I can undertake the treatment (afford it, lifestyle limitations); and Whether I will “get on” with the practitioner. 		

My Treatment Ready Reckoner

MEDICATION NAME for CONDITION NAME					
STOP BACKWARDS		IDLE NOWHERE IN PARTICULAR	GO FORWARDS		
RISKS > BENEFIT		NOT SURE		BENEFIT > RISKS	
This treatment will worsen some of my existing symptoms.		My condition will not worsen if I don't take this treatment. (i.e. it may not make any difference.)		If I don't take this treatment my health will worsen. I may suffer an acute event/I may narrow my options on treatment/I may not regain lost ground.	
This treatment will cause new symptoms.		This treatment will not make a measurable difference to my root problem and the main symptoms.		This treatment will address the root problems and symptoms that are taking me backwards.	
This treatment will worsen another condition I already have.		This treatment will make me feel better, but only while I'm taking it.		This treatment will treat or support the lifestyle causes.	
This treatment could cause another condition down the track.		This treatment doesn't treat or support the lifestyle cause/s.		This treatment will work within the time frame that I need to see a difference.	
		I can't be reassured that this treatment will “work” within any reasonable time frame.		I can monitor this treatment to make sure that it is working.	
		I can't monitor this treatment to see if it's working.			
SCORING THE OVERALL VALUE IMPACT					
<5: More risk than benefit; It may do nothing or it may take me backwards if its side-effects are as bad, if not worse, than my condition			>5: More benefit than risk; It will take me forwards/I may go backwards without it		
I could end up going backwards	4	I could end up going nowhere	6	I could get to where I want to be	10
	3				9
	2				8
I could end up going backwards, fast	1		5	I could move forwards but not very far	7

“ It's opened up a new dimension to the new relationship between patients and medical profession. I'm starting to take control of my own journey and being more proactive looking for sources of information and what questions to ask. We have to do our homework before we see any professional as no-one has the time to listen. At the start I was bogged down with things and just by making a few changes has made a dramatic difference to my stress and overall fulfillment. ”

Principle 5

Willingness

“ I am living everyday as a new day not as it may be my last. More positive and researching more of my condition and trying new strategies and diets, more positive to research medications and choose a more informed path. ”

The post training research showed us that many participants had indeed started their journey prior to the end of the training and were seeing measurable and meaningful results, and keen to keep moving forwards.

In addition to their health challenges, many of the participants had substantial obstacles to overcome but most were willing to give it a go. Solutions had to be do-able (within capacity), work (fix the problem) and be worthwhile (meaningful).

Solutions that meet the preconditions

When unpacking the starting point it was quickly established that sticking points for the journey focused around individual requirements that could establish an environment to support change. In every case, recurrent themes emerged which helped identify two key requirements for each participant, which ranged from support, space, order, strategy, purpose, direction, independence, communication, presence etc. These could become the “go-to” cue in times stress as a first line request to focus the direction. In the example, Case 24, there was a requirement for independence and support. The greatest friction in this case was the loss of independence due to the paraplegia and the unwillingness of helpers and family to give the type of support that was requested.

Capacity to predict the value of solutions

Willingness to try solutions was increased when there was greater capacity to predict the value of that solution to their case and show measurable benefits or be worthwhile. Within the context of the case and the journey reference points it was possible to ask key questions that would allow the rapid filtering of choices, and the capacity to monitor progress. Seeing achievement for effort was

a strong motivator for the journey, especially for more meaningful outcomes.

Motivation

Although we may have a high desire for change, barriers that prove insurmountable can undermine motivation. Participants were encouraged to unpack all their barriers and identify any personal criteria/behaviour patterns that could undermine progress. These then became the key obstacles (root causes) for moving forward. They were then asked to describe how that root cause could undermine the journey, then evaluate the possibility of overcoming the barrier and reflect this in their motivation score.

This often held the key to the journey. If the only solutions or way forward generated more friction then it was unlikely that the journey would proceed. If there was an unwillingness to look for better ways, and a stance of *I won't do it* taken, then any attempt at help would be met with resistance. How we communicate our needs to others within our immediate social environment may be the sticking point particularly when these relationships are driven by guilt or fear which often leads to anger or despondency and creates an environment that does not support change.

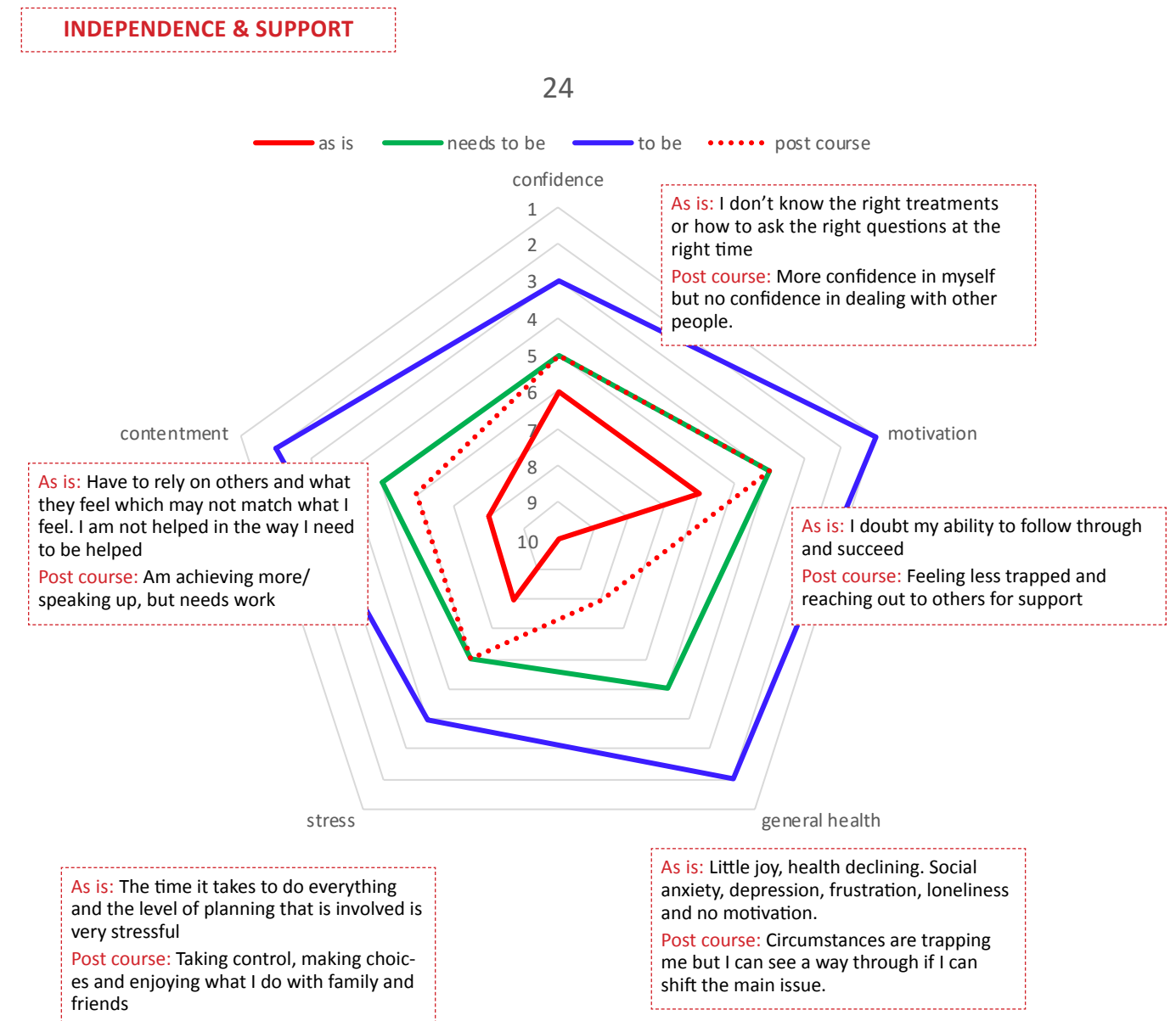
When there is a high desire for change, without thought to what it may truly take, as in case 26, then motivation may not be adequately stimulated, and the person may not reach any of their goals. A certain amount of friction is required to sustain the momentum and solutions that reduce friction to the point where there is little drive, can set the journey back. For example, reaching a point of acceptance can either enable the person to move on or, alternatively, make them give up.

Female
44 years
Full time employment
Dependents: 1 small child
Medical condition: Paraplegic, kidney/bladder issues, overweight, pressure sore, depression, bursitis/tendinitis in R shoulder

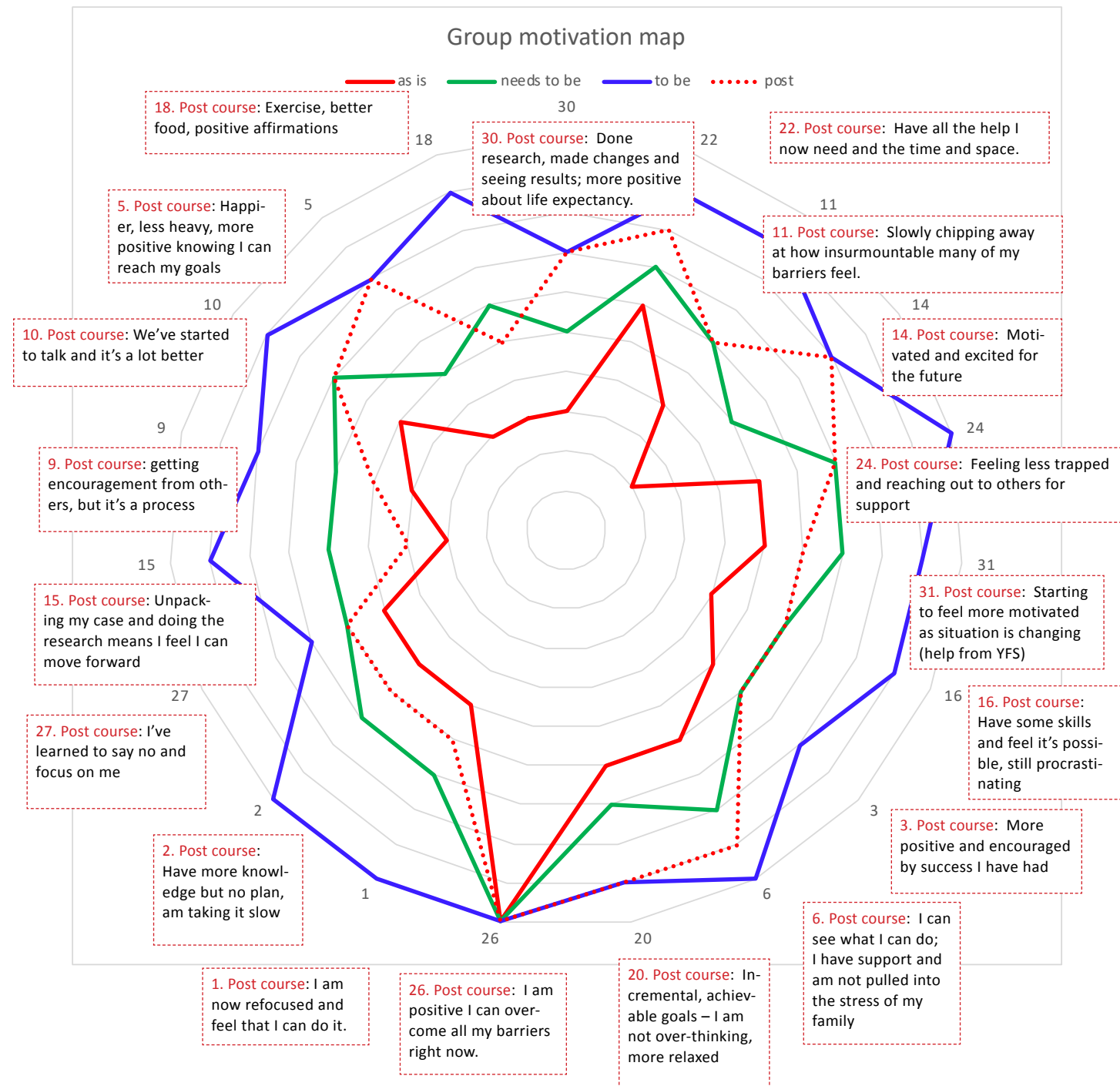
Solutions

Reaching out/accepting help when needed, open communication, NDIS, support, better food choices, putting self first, positive self talk, giving things a go, Botox surgery (bladder), healthy sleeping habits

Case 24: Overall Progress Radar Map



Group Radar Map : Motivation



Group Motivation: AS IS and TO BE statements

	MOTIVATION: AS IS	MOTIVATION: TO BE
30	Knowing that there's no cure and it's only going to get worse	If I could get sufficient know-how to manage my case and navigate the system and work with my practitioners this would make me feel better and that I could make headway.
22	I can't accept help and let other people take control of issues and for me to be OK with that decision.	Having the time and space I need for me would bring greater peace and ease into my life.
11	My biggest barrier is my health and how overwhelmed with pain I get - it erodes my morale.	I would have flow and ease and be more confident in my ability to stay steadfast.
14	Know-how: Don't know where to start - What I'm going to do differently.	I will achieve a sense of inner peace and be happy with who I am.
24	My biggest barrier is myself, my doubt and self confidence in my ability to follow through and succeed.	No longer holding myself back from being the best that I can be.
31	My son could mean he ends up in jail, hurting himself or us. I don't know how to help or what to do. I feel helpless/depressed/unmotivated, but I really want to help so my motivation is high.	Having the right know-how would enable me to help my son, have a safe home environment and be in a better place to help myself with my own health issues.
16	My biggest barrier is myself. I procrastinate too often.	Being sufficiently motivated to achieve what I want to would make me feel confident in the sense I can manage my life.
3	My biggest barrier is negative self talk and self doubt	More positive and focused
6	My biggest barrier is my nephew as it is impossible for me to move him out. He makes my life very distressing	Free from family stress would open up my whole life and give me the motivation and energy to write and be creative
20	Accepting help is the biggest barrier. If I never get the time I need for me I will continue to put others first and what needs to be done will only be done by me.	I would be relaxed, have more confidence and more enjoyment
26	I am positive I can overcome all my barriers right now.	I am positive I can overcome all my barriers right now.
1	Getting started and maintaining momentum is my biggest barrier	Proud and happy, enjoying life more, I would feel I could be a role model for others.
2	It's my self-doubt that holds me back	With more confidence I would be more motivated and happy and that I could have the direction needed to achieve my goals
27	I am doing too much and with helping my family, work and study I don't get a break - I don't know how to change this	Having physical and emotional balance in my life would mean more joy and greater health, better relationships and greater capacity to achieve what I need.
15	My biggest barrier is my health issues, not being able to find the motivation to start my journey.	Seeing positive change in my health would give more motivation. A treatment plan that works would mean that I could enjoy life.
9	Still at the time of finding strategies. Still feeling a bit of fear because not sure I can make it	Keen to look at myself and adjust myself at different circumstances
10	My biggest barrier is having the discussion with my wife	Peace that I am not meeting disapproval
5	I am my own worst enemy	I would be less heavier and happier in myself.
18	My biggest barrier is health issues and stress. Having gout minimizes movements, always eating junk food and buying soft drinks etc.	Having a meal plan planned out that is healthy - breakfast, lunch and dinner; joining a gym, exercise and sports

So What?

“ I question the doctors and specialists about my condition and do my research and this is getting a good response and my specialist has reduced frequency of visits. They are more confident that I can monitor how I’m going and how proactive I am being. My test results are all improved. ” [Case 30]

There is no doubt that the training helped most become more ready, able and willing to start the journey. They were able to formulate a coherent plan within the context of their circumstances, gain sufficient confidence to make informed choices, implement solutions that would support the journey, and gain the support they needed to succeed. We observed that solutions that create greater ease and reduce friction facilitated the journey and when the aspirational end point, or even the medical end point is truly reflective of that person’s aspirations, then the journey is more likely to stay on track.

Several participants did not implement many of their solutions, blaming their own inherent patterns of behaviour, such as procrastination or self-doubt, or even reaching a point of acceptance which did not require much change to occur on their part.

Realising the journey requires resolve, endurance and willpower. To be mindful of this, and to exercise this, has to be a key component for success, even if the steps taken are incremental but purposeful.

It may well be that we do not make decisions to overcome our resistance to change until the friction becomes too great and something has to give, by which time it may be too late to make a meaningful difference. Under these circumstances the burden of the failure to respond soon enough is carried by family, community and society at large. Although the training gave an opportunity to work out self-negating patterns, without the will and the sense of responsibility that a successful journey requires, then nothing much may change.

However, we did see some notable improvements in people’s health:

Case 11: diagnosed with fibromyalgia and taking medications which were making little impact. This raised the concern that the diagnosis may have been incorrect and instead of increasing medications, these were reduced and a pathway was researched to help find the right diagnosis and treatment.

Case 30: suffering from CREST and multiple organ problems. She was able to reduce her in patient hospital stays from 10 in the preceding 6 months, to one. There was no incidence of infection during the training. With the improved diet, there was weight loss. *I question the doctors and specialists about my condition and do my research and this is getting a good response and my specialist has reduced frequency of visits. They are more confident that I can monitor how I’m going and how proactive I am being. My test results are all improved.*

Case 22: Lupus, reflux, anaemia, DVTs and recurrent infections. No incidence of infection during the training, change of diet and had more motivation to stop the Nexium as this was impacting her iron and B12 levels. The anaemia normalised. *A better understanding about my health issues and how to deal with health professionals in what I want and need. It has helped manage my health issues in a better way and learn new strategies. Also learning about medications.*

Case 5: diabetic with very high blood sugar levels but reluctant to see GP through fear. She did go to the GP, is having her condition managed, has changed her diet and lost weight. Her entire family are now on the diet regime.

Case 31: diabetic. There has been a change in diet and removal of foods creating gut pain. She is more mindful of the steps she needs to take and her responsibility to do this. *I realised how shit-ass the medical system is and how little they do for me; no one is going to help you unless you help yourself.*

Case 20: continues to lose weight and also able to reduce her medications for blood pressure as she continues to improve. *It gave me the skills to handle & deal with things; more confident; not just relying on the doctor. It’s given me a different outlook; I am more open, and assertive/I can be true to myself and not always giving in to people.*

“ Health Commons changed my life. It was eye opening and it helped me make good decisions. It made me discover that I had diabetes and gave me the confidence to get diagnosed. It gave me support and when I had a goal I ran with it. I have done all the things that I put in place and I am happy. I now realise that I can be fixed. ” [Case 5]

Case 10: back pain/slipped disc from long-standing injury. Through careful inquiry he was able to find out that surgery would not be a good option which gave the motivation to stick with his exercise program where he has reaped many benefits. *I was able to get good clarifications of where things are.*

Case 6: anxiety. Was able to come off anxiety medications, find the practical support she needed, manage stress and make better health choices.

What remains to be seen is how far the participants progress over the next nine months, whether they are able to take their new abilities to navigate the system, find solutions, manage their circumstances and keep the momentum going, or whether being in a learning environment is a critical part for that motivation and if so, whether any future thinking would need to make some provision for this.

Case 27: requested an ultrasound prior to proposed surgery and the surgery was cancelled due to no evidence of disease. She is seeing a Chinese herbalist who is helping with many problems, doing exercise and addressing diet and stress issues. Her migraines have improved dramatically. This was a condition where she would frequently need to seek medical help and would present at the hospital on occasion.

Case 14: Overweight, thyroid nodules, fibroids. Now having TCM which has addressed many symptoms and is on a weight loss diet. *It provided valuable information in order for me to take control of my own health; highlights the need for me to be the primary decision maker for my health choice; my GP and other health professionals invest in treating the symptoms until there is a need to medical intervention.*

Professional Advocacy Training

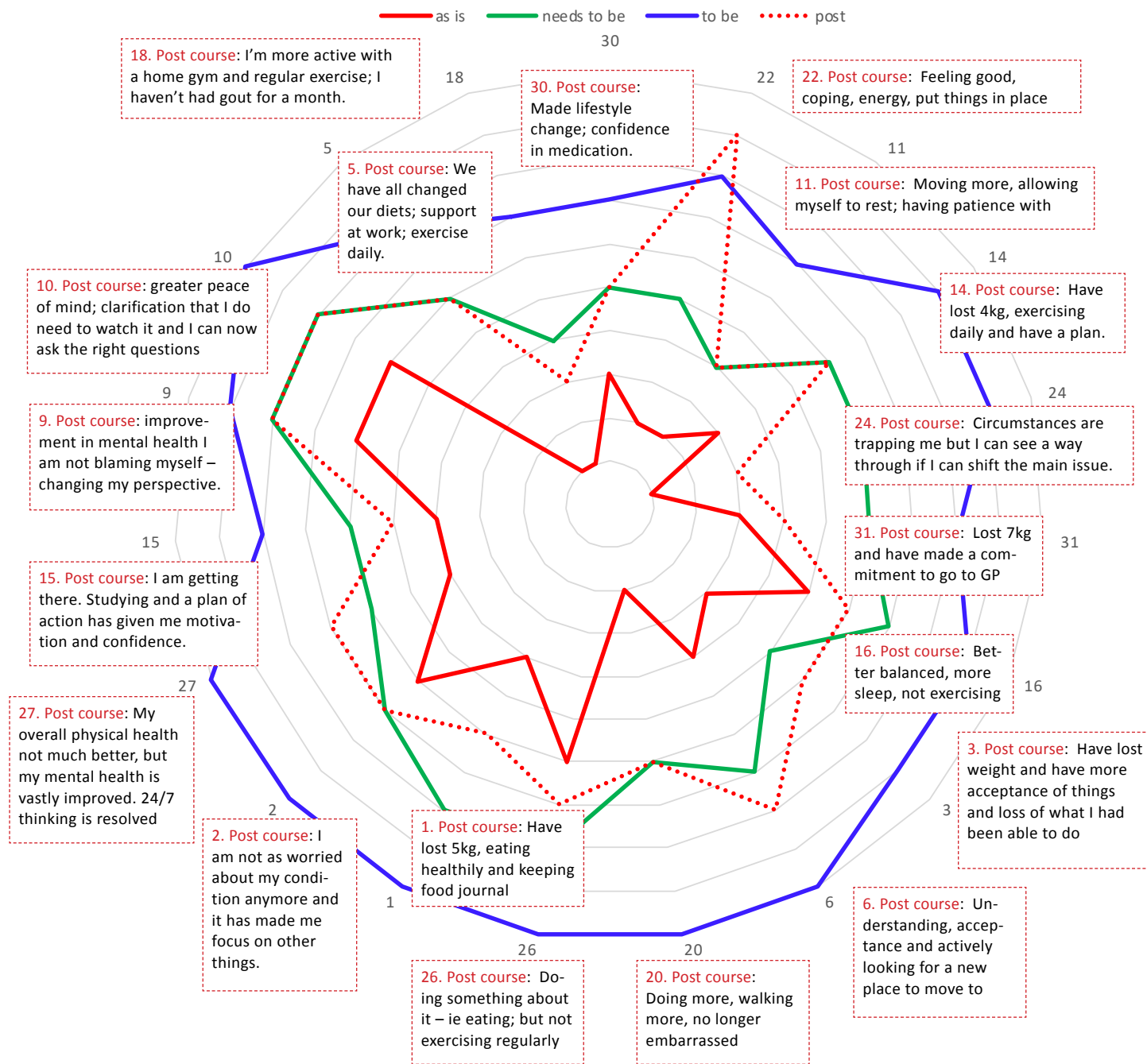
Due to COVID-19 the program was altered and instead of a weekend induction training for those participants who wanted to train in the method and become advocates, we restructured the course and its offerings. We developed the Ready Reckoner training which was a slightly cut down version of the course, but one that would fulfill all the requirements to help a person be ready, able and willing.

Only two participated, as most were too overwhelmed with work. A third participant was a dietetics university student who had been on an earlier course. We ran an online training over a period of 5 weeks and developed and published training materials, which included the Health Commons Ready Reckoner, Course Companion Guide, video tutorials and survey templates. The training also offered mentoring with clients and some of the client results will be produced as part of the final report. The professional advocates have been invited to submit their experience and comment on the potential value to health professionals working in their field.

Group Radar Maps

Group General Capacity Radar Map

Group: general capacity



General Health Capacity: AS IS, NEEDS TO BE and TO BE statements

	HEALTH CAPACITY: AS IS	GENERAL HEALTH CAPACITY: NEEDS TO BE & TO BE
30	My pain and shortness of breath makes it difficult to do things, limits my social life, time with my children, can't exercise and affects my sleep. My energy is very low and I feel depressed. I am embarrassed by the amount of medication I have to take.	Better focus and more energy to work the whole day. Better able to unwind and sleep better. One hour of me time a day. To join in and be social. To be pain and symptom free without medication and refreshed with the energy I need. This would make me happy with more self-confidence.
22	My condition means it is hard to cope with work and family. I take a lot of time off work, now without pay. I may not be there enough for my children as much as they need. I am tired and when emotional, I want to overeat.	Being better able to function during the day and not being so tired. To be at work instead of appointments and taking days off. Less stress and more energy to spend time with my kids and doing things for me. To feel strong and well to combat infection.
11	I am in pain from my joints and recurrent dislocations. I have disabling migraines and fatigue. My motivation and sense of optimism leaves me feeling hopeless. I can't work, and I am not the best partner one could be.	Find gentle ways to move and be more patient on my bad days. Gain more motivation & optimism and find ways to be less angry. To be in charge and knowledgeable about my condition with more ease of mobility.
14	I feel isolated socially. I feel ugly, overwhelmed and anxious over small things. I have little motivation, I overeat and do little exercise. I am worried about being able to function physically and socially.	Lose 3 - 5 kg, find an exercise regime I enjoy that gives me good outcomes for how I feel about my health and able to move forward. Could do weight watchers / prepared meals. To confidently participate in activities that give me energy and motivation; to enjoy a diet that gives me the nutrients and energy to enjoy life and socialise with friends.
24	I am wheelchair bound & limited in what I can do, everything takes longer to do. I have to plan my days around bathroom access. There is little joy and my health is declining. It creates social anxiety, depression, frustration, loneliness & no motivation.	Looking after me – more activity and better nutrition. Plan time-management and put in diary self-appointments -one day / week; and to put in time for meal preparation. To have the freedom and capacity to choose what I want to do, and feeling motivated about life would make me feel more human again. And perhaps even get a job.
31	I am not confident, I have a serious health issue and am totally unmotivated	No smoking at all, maybe start some gentle exercise, eat more non refined foods. To feel good in my body and dress in what makes me feel good. To feel confident that my condition is under control.
16	My low energy means that I can't do everyday things with ease and I can't overwork; it makes me stressed and I am less social than I would like to be. Poor sleep and heavy periods make this worse. I am anxious about a recurrence of cancer.	To have better sleep and take supplements to help; improve my energy, start exercising, walking 4 times a week, to eat well and follow up on check up. To know what I am doing is on the right track and will protect myself in the long term so I can keep my health.
3	I struggle to do normal things without a great deal of effort & strain. I feel a burden on others, including my partner. I am in pain and have mobility issues. I am no longer participating & feel socially isolated. It's difficult for me to accept help.	Ease of movement, weight loss of 10KG, self acceptance that I am doing the best I can with what I currently know. To have freedom of choice and being able to do what I want when I want, easily and without preparation. Being able to participate fully in life.
6	I get anxious and extremely stressed; I shut down and isolate myself. I have little joy and my heart feels dead. I have many responsibilities for others.	I need to learn how to relax, manage my mental health and anger so I have circuit point. To be able to relax in my own space would give my life pleasure and provide happiness. I will be able to sleep without assistance.
20	I am embarrassed and feel self-conscious about my weight. It stops me from enjoying life and doing things. My knees ache and I tire easily. I feel concerned that I am stopping my partner from doing things.	I need to lose 10kg, go to the gym and stick to the exercise program. I need to walk more, support from my husband and understand what I am doing and why I am doing it. Being able to enjoy life with eagerness, motivation and spontaneity. To run around with my grandson and do exciting activities, pain free.

General Health Capacity *contd*: AS IS, NEEDS TO BE and TO BE statements

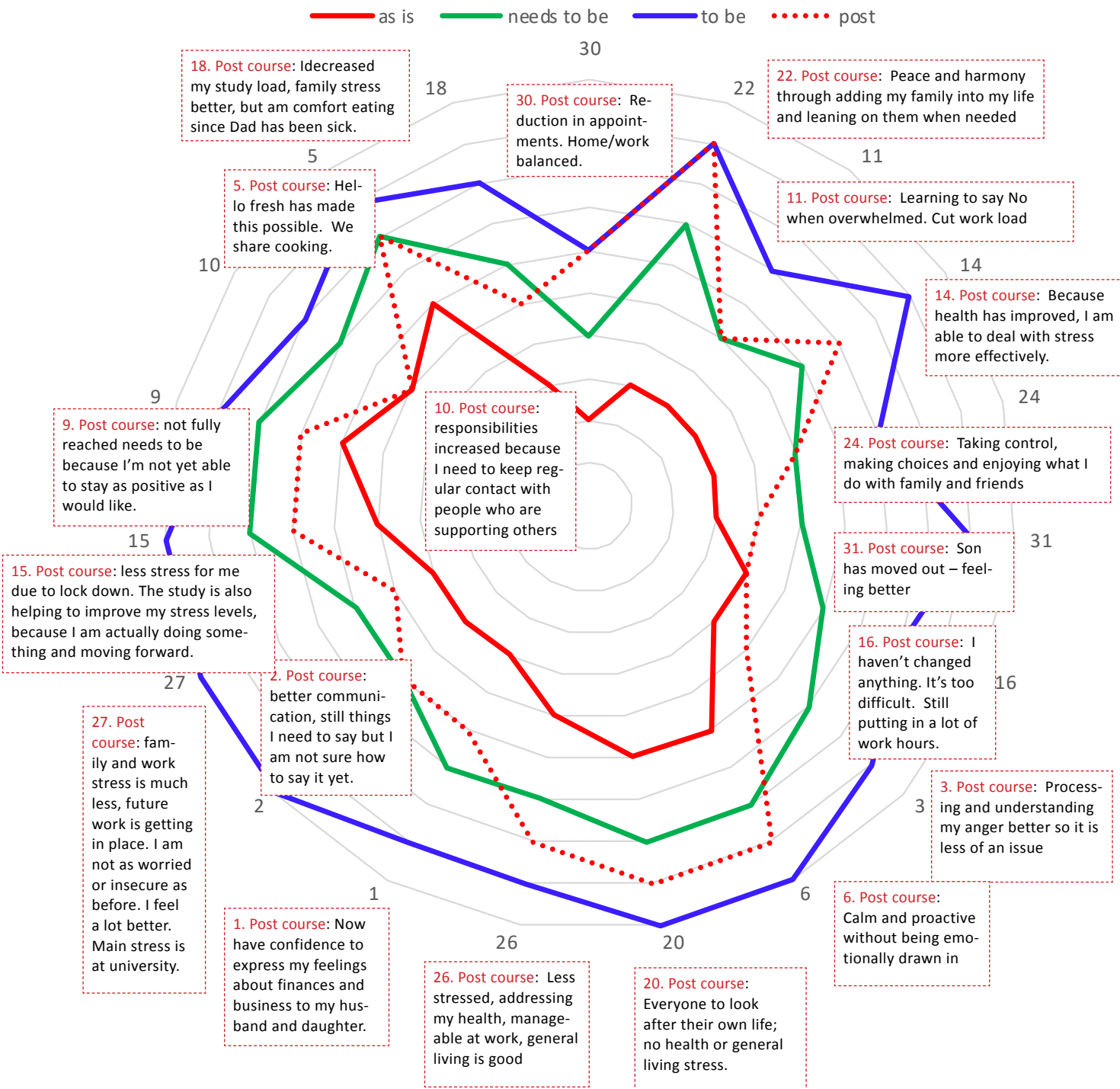
	HEALTH CAPACITY: AS IS	GENERAL HEALTH CAPACITY: NEEDS TO BE & TO BE
26	I worry about my future health and although I have lost weight I have lapsed into bad habits through comfort eating from stress and not exercising any more. It's hard to stay motivated.	I need to commit to a routine that will allow me to have regular daily exercise for at least 30 mins. To be confident about managing my health and optimistic about my future.
1	I have poor mobility & balance due to knee/ankle pain which makes me lack confidence. I have poor energy & don't cope as well as I would like with daily chores. My weight impacts my life & I worry about diabetes as I have to monitor my blood sugar levels.	Lose weight, exercise more, eat less fats and carbs, find the right diet and not do the cooking for the family. Feeling confident and good about myself, having the mobility and the energy to walk and do activities, having the confidence to be in control of my health.
2	I never know when my condition's going to flare up. I don't feel like I have control over my condition and others see me as my condition. I feel worried about my future and discouraged about my future. I've lost motivation.	more motivation to apply for jobs. To have direction and purpose in a job or role that I would love. This would make me feel free and independent.
27	I am not a happy person and the quality of my life isn't good. I have intense migraines with vomiting and have to go to emergency sometimes for injection. I have an endometrial polyp and need surgery which is very frightening for me	To have less severe headaches and be able to manage them. To get enough information about my condition (polyps) to make a decision. To have energy and less pain so I can live my full potential. To feel and look better, being both physically and emotionally balanced would bring joy and happiness to my life.
15	I am stuck and have no motivation to move forward. I don't like leaving the house. I have anxiety and no confidence.	To get some support, get my condition under control with a treatment plan to give results, get my driving license. To feel motivated and in good spirits, looking good and going out with my friends. Having confidence knowing I have the right treatment and security having a job.
9	I am not able to predict the moment the allergy happens, which might restrict me from going out with friends, dealing with daily life and sorting everything out on my own. It can make me very tired and hard to do normal things.	To have more understanding and awareness of what triggers my allergies. To be kinder to myself when the allergy happens and not blame myself. Start being more active. To have greater resilience and normality.
10	conscious of my back, I have to think about bracing myself, but it doesn't stop me from much. I am not too confident about my future.	Not to be checking myself so much before I move. Find out what the surgeon can do for me and what my options are. Peace of mind that what I am doing to maintain my health is the best possible I can do.
5	I'm overweight, worried with churning brain; no energy and can't do much; I am useless and upset. don't sleep - my lungs get squashed	Change in eating, up my exercise at the gym and stay focused, help with what to cook, help with shopping list and where to go, need to find a support person who cooks and shops. Feeling lighter and confident to do more physical activities. Knowledgeable to help my family.
18	trouble breathing, no energy to do simple things, and I can't stop eating junk food. It's difficult looking for jobs because I may have to take time off work.	Finding a diet that works for me with a few kilo weight loss Being healthy, maintaining a good weight and being confident about my own body. I would like to be a size 12-14. I would feel over the moon and enjoy my life more.

The problem for the patient is not the illness, but how they're going to deal with it.

Kathryn Alexander
Founder of Health Commons

Group Radar Map: Stress

Group Stress map



General Stress: AS IS, NEEDS TO BE and TO BE statements

	GENERAL STRESS: AS IS	GENERAL STRESS: NEEDS TO BE & TO BE
30	I always feel like I am in catch up mode due to work life and medical appointments. I feel inadequate and not able to cope doing my job with my illness.	Better able to balance my time and deal with work commitments; not bring work home; not have my family influence my health decisions. A balanced work and home life and the confidence to share with my family my health concerns knowing that they will support me.
22	I don't have time to deal with everything in life, work or personal life. This means I am run down and can't deal with myself at times.	More time to myself, not bring work home, try and debrief, go to bed earlier, leave house work until later, come home to a stress free house. To have greater peace and harmony that would allow me to have more energy for myself and my children.
11	Constant exhaustion, irritability and tension which makes my pain worse. I am not a good reflection of the self care I espouse in my career.	Become more assertive with my work / life balance, find a supportive environment, find a way to manage demands and pain levels. Feeling better and authentic with pain management and motivation to practice self-care.
14	I take on the worries for everyone else. I am the go to person who has to fix everyone's problems or issues. I feel anxious all the time about letting people down.	Able to focus on myself and accept that I do not need to take on other people's struggles and let it affect me so deeply. Find something to focus on. Greater freedom and peace, and a sense of internal balance where I can have confidence in life and others around me.
24	Just trying to incorporate everything that I need to do – which are all stressful factors – all at once. It's the time it takes to do everything and the level of planning that needs to be involved to do anything.	Get a routine. Take control of my own life and not leave it up to others. Give me the time to enjoy things more, spending time with my son and friends.
31	Life is in tatters; I don't know what to do	I don't know how to make it better, but would like to help my son so he can move out so that we can have a normal life and my daughter is happy. For me and my daughter to feel safe, living a normal life free of drama, with greater peace and harmony.
16	My biggest stress is work, life and family balance. Bringing home work eats into my family and upsets my husband and I feel stressed and guilty. My husband's cold attitude towards my mum and brothers.	Cut down on working hours, better manage tasks at work, achieve a balanced relationship with mum and brothers. Having a good work life / family balance and a varied diet to socialise with family and work occasions.
3	I am frightened, lonely, frustrated and angry and my health stresses me.	I need to be healthier, safe, less angry, at ease, able to exercise and keep learning. A better sense of ease within my life would make life pleasurable and enjoyable.
6	Nephew in house is lazy, dirty a liar and steals. Constant worry he will suicide. I have house work overload and care of my mother. I feel insane, angry, unloved, no direction, sad and no time for myself.	I need to organise my mind so I can manage my nephew and my mother's care. Deal with nephew's mental health to help him be motivated and independent. A peaceful life where I can concentrate on relaxing, building my direction and feeling great self worth.
20	Dealing with my siblings arguing, sorting out dad's estate, trying to build a house. I feel like I am in the middle and trying to do everything on my own. I am tired, anxious and overthink everything.	I need to step back, ask for help, go for walks and talk with others, not keeping it to myself. To feel joy, love and involved, enjoying my family and doing things for me would give me the peace and relaxation I want.
26	At work I worry about funding/budgets/grants. I am concerned about my health and future and my general living stress leads to over-eating / comfort eating.	I need to run regularly and eat better foods. To be at peace with everything in my life.

General Stress: AS IS, NEEDS TO BE and TO BE statements

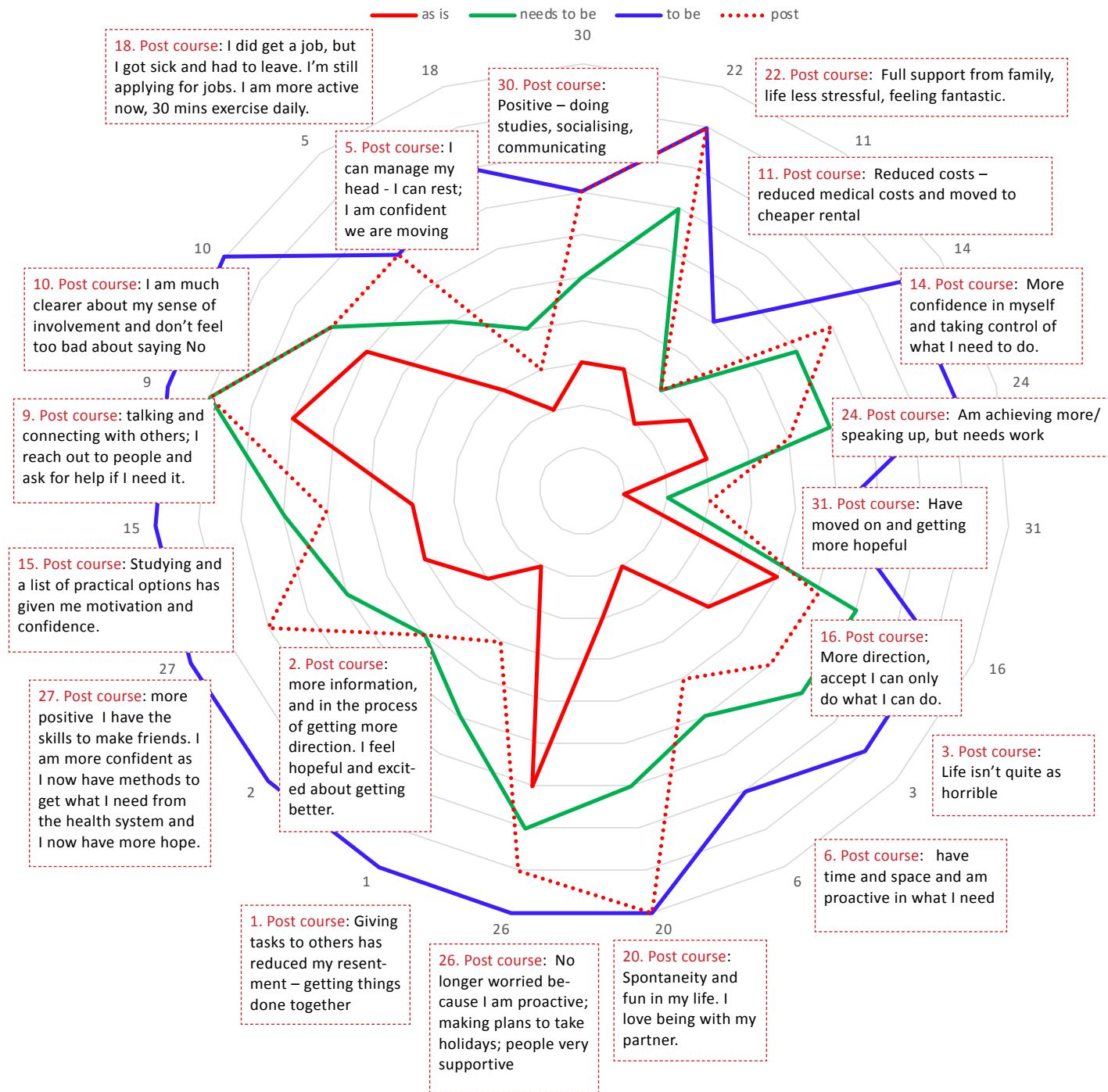
	GENERAL STRESS: AS IS	GENERAL STRESS: NEEDS TO BE & TO BE
1	I procrastinate and can be late. I rush and can make mistakes. I often feel that I fail and this makes me not like myself. I am also insecure about my finances because I have no control over these. I am frightened of Ray's health.	To get on with things asap. Set my own time-lines, before the official time lines. Set targets. Budget. Make good food choices and work with Roy for the finances. Feeling liberated and free, being sure of myself and ability to achieve things. Feeling confident and enjoying life's challenges with the health security I need.
2	Because people can't see my condition they think I'm faking so I feel unfairly judged by my family in regards to employment. When this happens I feel powerless and my family take their problems out on me.	Better communication in knowing how to broach the subject. More understanding and better communication when there's a problem with more loving and caring connections.
27	I'm stressed about looking for a job; my dad is going to have a bone transplant in March and I am stressed about this and having my own surgery. I am really scared. I am lonely as most of my friends have left Brisbane.	Find a job I'm good at; settle on whether I have surgery or not; for my Dad to get his health back Having the support I need would give me greater connection and harmony; and having the information I trust with give me confidence to manage my health.
15	I am anxious about the future, about being unemployable, having no freedom and being a failure.	Feel confident enough to look for work. Having confidence and independence would make me happy and feel like I am contributing.
9	The expectation from my family pressures me if I can't 100% become the person I want to be and that could affect the way I make friends with others.	To find different lifestyle activities, have more positive frame of mind and even when stress happen to try to stay positive and not think it is the end of the world. To have balance and feel good about myself knowing that I have the ability to reach my goals in life.
10	I have competing responsibilities and interests and I want to do them all. I find it difficult to say no.	To prioritise and say no. Clearly outline my responsibilities, pull out of some and feel good about it. Put limits on my responsibilities and feel at peace when I say no to demands.
5	Uncertainty/fear for future health for all; stressed about what to cook and where to buy good, clean food	Find an expert, find people with the same needs as me, cook together and an easier way to shop. With the confidence to look after myself and my families health and the ability to teach others in my family a better way of living would make me very happy.
18	Trying to find a job to help my family out and with uni coming up I will have a study load	To get more motivation so that I feel I can move forward Being able to be financially stable and independent would make me feel happier and on the right path

Dealing with the peripheral issues helps you put yourself first as a focus.

Case 31

Group Radar Map: Contentment

Group contentment map



General Contentment: AS IS, NEEDS TO BE and TO BE statements

	GENERAL CONTENTMENT: AS IS	GENERAL CONTENTMENT: NEEDS TO BE & TO BE
30	Each time I go to a specialist they want to add a new diagnosis and new medications which means more side effects whilst trying to maintain my job. It makes me feel frustrated and more doomed.	Better able to deal with diagnosis. More focused on what I can do and can be done with family time. Activities I can do as a family and as me. To feel empowered, confident and safe with minimal specialist appointments, tests and surgeries.
22	I am always thinking about my health but doing nothing as time and dealing with my children first as I am the go to person in the family and ensure everyone is looked after.	I want to make my family responsible and ask for help when needed. Enjoying the care and support that I need would bring me relief and increase my sense of contentment.
11	My condition is only going to get worse and I have no financial security or relationships that I can lean on. I feel trapped.	I need to find a way to get more money and work through trauma and disappointment. To have more peace and ease with my situation, to have understanding and more confidence that I can manage my health.
14	I feel uncertain about the future and worry about the perceptions of others. I constantly compare my life with others and focus on the things I don't have.	To be free of thoughts that affect that way I view my life and how I see my success (work family and health). Find support. Happy with my life and feel relaxed with who I am and what I have. Feeling that I am good enough.
24	Have to rely on others and what they feel which may not match what I feel. I am not helped in the way I need to be helped	By not feeling second best and speak up and saying what I really want and need. To help people understand where I'm coming from and why. No more procrastination and put something that I want to do or achieve in my planner and find a way of achieving this. A greater empowerment would make me feel like me!
31	No hope, I don't care if I don't go on	I have no aspirations, I obviously do not deserve it. Maybe if I was not here - perhaps that is my contentment. For my girls to be OK is all that I can really hope for. I want to be happy.
16	Sometimes anxious about my health future and how it affects my family. Worries about my daughters health	Empower myself, think clearly, learn more things and help my daughter to take care of her own health preventing breast cancer. Having clarity of thought and optimism, being able to help people around me especially my family would bring me joy and reassurance.
3	My health undermines my contentment, I feel frustrated and a burden on others, frightened and uncertain about my future health security.	Weight loss happening, self understanding that Rome wasn't built in a day and daily regular exercise. With improved health I will be confident, hopeful and positive for my future and able to enjoy my life.
6	I am angry so regularly that there is no peace. I am unable to sit in the lounge when my nephew is there and enjoy mother time. I have no space of my own.	Some space to write, put bullet points in a diary, get some chickens and put up wind chimes. Having my own space to study and write will give me spark, passion and energy.
20	I am always trying to be a peacemaker. I end up running around in circles and I am frightened that I will not be able to do things.	I think if I was more open and talked about things then things would improve. To feel free, confident and hope would bring me greater fulfillment and certainty for the future.
26	Overall contentment is good - the only area not good is health security. I feel anxious worried and uncertain.	Immediately address my health security by running regularly and eating healthy foods. With good health I know I will be able to live a happy, fulfilled life for many years.

General Contentment: AS IS, NEEDS TO BE and TO BE statements

	GENERAL CONTENTMENT: AS IS	GENERAL CONTENTMENT: NEEDS TO BE & TO BE
1	Feeling of always having to cover up the fact that everything is left to the last minute. Denying myself satisfaction of success. I feel I am not reaching my full potential.	Cull activities; let things go; give myself a reward when I achieve things. Feeling fulfilled, confident with good temperament. Walking through life with ease with a sharing relationship.
2	I feel trapped like I'm not going anywhere. I feel too comfortable where I am and it's stopping me from doing better.	More knowledgeable would give me hope and ability to act. I need to research or ask for help To have direction and purpose would make me feel liberated, involved, worthy and motivated. I'd like to feel reassured about my health.
27	My community left Brisbane and I feel sometimes lonely with lack of security. I feel lost and insecure in my health.	To find a practitioner I can trust. To put myself out there and socialise more and have hope to find a new community To be involved, have connection and joy. To have confidence and be reassured about my condition, would give me hope.
15	I feel stuck in my life like it can't get better. I feel discouraged in my treatment. I feel like a burden to my friends.	To feel a little more hopeful with treatments that work. Content with life, having a job that gives me purpose would give me the independence I need.
9	Though I feel satisfied most of the time I just feel insecure if the connection between people are lost. When I have allergy symptoms I can feel trapped.	Strengthen and deepen the connections with people. Get help if I need it. To feel supported with a group of friends, to feel empowered and have greater satisfaction in all aspects of my life.
10	I am challenged when I doubt my ability to meet my competing demands which I sign up for.	Know and state clearly the reasons for making the decision I make. Enumerate my commitments, place boundaries on those and withdraw from some. I don't have to say yes to everything. Confident and clear about commitments, what I would like and able to involved in and what I don't, and be at peace with my decisions.
5	My head doesn't rest; it keeps me awake trying to work out my own solutions for fix my future and my children's future	Less thoughts going through my head in a negative way, positive thinking. To have the positivity and calmness knowing that I have done my best as a mother.
18	My health undermines me the most because it will impact me in the future, and it's stopping me from getting a job	Hopefully have a job and feel more active than I am today With greater health security I would be confident in my own body to be myself.

Knowledge [of what works] will become the enemy of disease.

Sir Muir Gray,
Director of Clinical Knowledge of the UK's NHS

The Training

There were two groups involved in the training: the first group had 19 enrollees of which 13 completed the training; and the second group had 13 enrollees of which 6 completed the training.

Of the 6 who failed to complete the first training, we had a couple of early dropouts after session 2 (case no 29 and 7), and one after session 4 (case no 13, a lady who had learning difficulties), and some who did up to week 7 or 8. At this point the course switches from unpacking the case to determining which treatments and lifestyle changes would deliver the best value. Although we tried to contact these people (case no 17, 25 and 28) to see if we could get the post course scoring, only one (case no. 5) did opt back into the program at a later date, and we have included her scorings within the post course summaries. Only two people gave reasons for opting out where time was an issue for one, and the training was creating comprehension difficulties for the other.

In the second group, due to CoVID-19, the training sessions continued on-line via Zoom after session 3 and I suspect that this played a part in the numbers who dropped out. Two people did opt out after session 3 (cases 32 and 19, both elderly) and the reasons given were that they thought the course addressed medical conditions and treatments for those, including healthy lifestyle, and they were not expecting to have to unpack their barriers, which they felt were irrelevant and a waste of time. Three participants (case no 8, 12, 21) may have continued, but case no 4, for whom I agreed to hold separate online sessions, did not commit to the sessions. He was trying to give up a smoking addiction and his life was very stressful at that time.

Of the 19 who completed the training we saw marked improvement in motivation and for several of the cases, better navigation of the system and self-management of their conditions. All of the participants embraced the notion of lifestyle change being pivotal to their journey and many had started to implement their solutions well before the training ended.

Part 1: Sessions 1-6

Session 1: Unpacking the Journey

Where am I now, and where would I like to be?

This session focused on scoring the impact of four of the five key determinants that have significant influence on the health journey:

- general health;
- stress;
- contentment; and
- confidence

Confidence related to how equipped a person felt to manage their health journey and was measured on a scale of 1 – 10 where 1 = *I don't know where to start* and 10 = *I know exactly what to do*.

Using real life scenarios to describe the impact of their unique circumstances on their lives, what it meant to them and how they felt, served the dual purpose of giving meaning to the journey (*what would I like my experience to be and what would with mean to me*) and informed of the type of solutions that would work best (what do I need).

The exercise gave the opportunity for participants to look at and consider their situation, focus attention on the experience/problem that was common to two or more key determinants, think about solutions that would offer the most value in reducing the pain and, having done this, to see the possibilities. Looking and seeing are both prerequisites for taking action to realise the journey.

Direction was given to help unpack, describe and score the impact of general health, stress and contentment. This was done to reduce the friction of unpacking the case, particularly in cases where a person had so much going on that they didn't know where to start. By dividing their current experience (starting point) into these three categories, it made sure that every impact was covered and gave greater comprehension to the root problems.

For example, stress invariably impacts general health and contentment, but the full ramifications may be under-appreciated and therefore it may not be a key consideration in the solution-set. By visually seeing the inter-relationships, it becomes easier to create a solution-set that has a greater chance of reducing pain.

We prompted participants to review lists of potential types of personal and social consequences that each impact (health, stress and contentment) could have on one's life. Participants were asked to consider the ones meaningful to them before crafting and scoring their statements. See Advocate Scoring Survey

Contentment was more difficult to unpack so we divided this into four broad categories, sense of fulfillment, independence, inclusion and health security, and we gave direction on the potential impacts to help participants define and score their experience.

The To Be statements also focused on the experience *What would I like my experience to be/what would this mean to me?* to create a single thread measuring progress against experience. The importance of this is because there is a tendency, when describing life events, to measure the intensity of the circumstances (how bad the circumstances are) rather than the experience. We found in earlier programs, that situations arose where the circumstances did not change substantially, but the experience did. This taught us that a successful journey is not singularly dependent upon a change in circumstances but also requires a change in experience, while bearing in mind that the two are often co-dependent. As we all know changing our circumstances is not necessarily synonymous with a better experience.

The grounded research from this first session combined with the post course research made it possible to identify the individual preconditions that would need to be met before the benefit of anything else could be realised.

For example, a working mother of two young children, one pre-school and the other of school age, with a FIFO husband, may have difficulty coping and not have the time to think about herself. The prerequisites for a successful journey may be support and space. Therefore, solutions that can deliver this would be pivotal to the journey. Participants who were able to find solutions that addressed their preconditions were able to start making meaningful progress prior to the end of the course. Those participants who were unable to engender that type of support (being in an environment that doesn't support change) struggled to get meaningful outcomes. Invariably, kind support from others was sufficient to meet the preconditions, and the practical solutions selected provided the means.

Unpacking solutions

The model focuses the participant on the first step, where they are encouraged to think about what the intensity of the experience/impact needs to be reduced to so that they can simply cope better/look at the situation and, secondly, what could help. Those that were prepared to take incremental steps, using solutions that were focused on reducing the pain, were able to make meaningful progress.

Several participants commented on the value of shifting from the all or nothing attitude, to one that was focused on incremental change, where solutions that support incremental change can dramatically unblock the journey, enabling the person to see the possibilities which can change the direction and motivate the journey.

Case 11

It has given me space to sit with my frustrations and feelings, and then allowed me to look at my health and life problems from a wider lens. I have been able to make incremental choices and changes by letting go of an 'all or none' mentality and instead focusing on what are the options available to me, and how they fit with my priorities.

Case 6

It gave me the ability to be brave. It gave me clarity and confidence to break old habits and create something different to help me that is mentally and physically healthy. The bite sized pieces that the course has provided has

enabled me to understand and put in place my strategy that has really worked for me.

The key requirements for change:

- sufficient meaning (based on improving experience) where decisions are purpose driven to drive change; and
- being in an environment that supports change

Solutions that may have the biggest impact will fulfill these criteria:

- meet a precondition
- fix or reduce the problem; and
- reduce the pain

The value impact of solutions that address all criteria may exceed any individual benefits it delivers, where the whole is greater than the sum of its parts.

Session 2: Unpacking the barriers

Session 2 of the training focused on the barriers, scoring the impact of their circumstances, both social and personal, on their journey. They were asked to select six top circumstances from a list, describing the impact and scoring the experience of each, using the scoring methodology as described. Once this exercise was done, participants were invited to score their motivation which was measured on how positive they felt about making the journey a reality where 1 = I am not at all positive and 10 = I am very positive that I can get to where I want to be.

Motivation is often scored as a measure of need, particularly if the stakes are high, but in our model we measure motivation relative to the difficulties, where motivation is easily undermined if the barriers are too difficult to overcome. Therefore, in order to get a realistic measure, we scored motivation after they had unpacked all their barriers and identified potential solutions that were within reach so that they could review their overall positivity within that context.

The barriers were grouped into two sections: social and personal (Table 1. Group percentages impacted by each barrier). Other than health issues themselves being a significant barrier, social circumstances, including know-how, were not found to be key barriers for the health journey.

Table 1. Group percentages impacted by each barrier

CIRCUMSTANCES	Percentage of group
<i>I would if I could</i>	
Affordability	35%
Accessibility I have limited capacity &/or require help/rely on others to get to where I need/ source what I need/get the resources that I need/travel is difficult	20%
Know-how I am unfamiliar with the system, don't know who to ask/who can help/what to do, I don't understand my condition or options, I have limited capacity to understand (eg. language barrier, too difficult for me), I have insufficient skills to do what is required.	55%
Work/study My work/study situation makes it difficult: I travel/am away from home, work long hours; have to socialise a lot	15%
Safety I am subject to domestic violence, intolerance (racial or otherwise), bullying, live in unsafe environment	10%
Rights/culture/eligibility I am unsure of what I am entitled to/cannot exercise them, my culture/religious/other beliefs inhibit me	10%
Support (family, friends, community, services, health services) I am unable to get the help or support I need from family/friends/peers/community groups or services (including health services), in order to make my journey possible	50%
Health issues/stress I have physical/mental/emotional health issues/disabilities or too much stress which stand in the way of doing what I need to do	85%
PERSONAL CRITERIA	Percentage of group
<i>I am my own worst enemy</i>	
Over-committed/time-poor I choose to take on too many commitments/responsibilities (work, study, social, volunteer work or family); I have difficulty in saying No; I find it difficult to prioritize my time.	35%
Doubt Efforts may be undermined by: uncertainty; fear of failure; nothing's ever worked before; negative self-talk; pressure from expectations; being easily distracted/procrastination; may not be able to stick with program; may not be able to change my habits/way of doing things/lifestyle/give up my addictions; I would if I thought it could work.	80%
Putting self-last I don't put myself first &/or prioritize my health or needs; I tend to put myself last/put others first; I feel everything is always up to me	65%
Accepting help I find it difficult to ask for help; I am unwilling to accept help even if I need it; maintaining my independence is an issue for me	60%

In an earlier training that we ran for a small group in Logan, we learned that motivation for change was undermined more by personal criteria, which included willingness to change lifestyle habits, and cultural and personal expectations. From this grounded research the barriers list evolved to encompass both social circumstances (I would if I could) and personal criteria (I am my own worst enemy).

Within the context of the starting point and their defined aspirational end point, participants were invited to unpack what could stop them getting to where they wanted to be and what solutions they may need to get there. Working through the personal criteria they were invited to consider *What is my part in this?*

When the personal barriers were unpacked and the raft of problems these created identified, it was found that these underpinned many of the circumstances' barriers. These are some examples:

1. Support: insufficient support was a barrier for 50 percent of the group, but a root cause barrier lay in asking for or accepting help which was experienced as a fear of loss of independence or control.

2. Health issues were a significant barrier impacting 85 percent of the group where participants ranged from having conditions that seriously impacted day to day living and lesser health issues that were manageable but undermined the overall quality of life and raised anxiety. However, the experience of frustration for most was underpinned by a lack of motivation, which was underpinned by procrastination, negative self-talk/self-doubt, poor time management/lack of prioritisation for self-care, and the inability or fear of saying No in order to create the space required for change to occur.

3. Know-how was broadly translated by the group as knowing what to do and therefore mirrored confidence (I don't know what to do/ask/where to start). However, the frustration also involved personal barriers such as self-doubt and procrastination and also prioritisation of time.

Looking through the barriers lens in this way gave greater comprehension to some of the root cause barriers and led to key solutions that could impact many barriers and get the ball rolling. At the beginning of the course we were

met with *Well where do you want me to start?* as the journey was seemingly too big and too impossible. But by unpacking all the barriers and getting to the root cause barriers, many could put in place a coherent plan that allowed for incremental change, where they went on to firstly see and then experience the possibilities.

Participants were encouraged to cross reference their To Be descriptions of what they would like their experience to be with the overarching aspirational (To Be) statements from the first session for general health, stress and contentment, as these provided the lighthouse for the general direction of the journey.

Sessions 3 & 4: Unpacking relationships

Sessions 3-4 focused on scoring the impact of relationships on the journey, which included close relationships (family and friends), professional relationships and relationships with those you don't know (broader public).

Following our experience with the initial small study group when we unpacked the barriers, it became apparent how powerful a role the personal barriers play. Many of the personal barriers hinged around being unable to say No or put oneself first which creates friction and resentment in all relationships. Communicating our needs, particularly when these underpin the preconditions for the journey, such as seeking support or space in order to help change happen, can be mission critical.

We decided to integrate Marshall Rosenberg's Non-Violent Communication method, a no-blame approach that allows us to unpack and communicate our core needs, making it possible to ask for what we need in a way that is likely to get that need met. Asking for support, space, respect, understanding, compassion do not come easily for many, but the relief when these things are acknowledged and the wealth of human kindness that is experienced as a consequence, may be all that is required to get the journey moving. We found that this was a key factor in facilitating and bringing joy into the journey. When people were living in an environment devoid of kindness, whether at home or at work, then progress would be slow or not occur at all.

The sessions gave the opportunity to unpack and review the needs along with potential solutions, and create requests that would satisfy those needs, whether of yourself

I am going to prioritise my time because I need more space to do....

or of others

I am struggling/short on time/overwhelmed at the moment and need ...[support/space].

Learning to ask for what one needed reduced friction (intensity of the experience) within relationships and was instrumental in enabling the preconditions for the journey to be met.

Some examples of the impact when needs are met:

I have had a shift in prioritisation to do the exercises I need to keep me well. Before it was always a chore that had to be fitted in; now it is part of my routine.

I have more energy, there is routine in the house and the boys are pulling their weight. I still need more time and space to focus on my health but my job is consuming. I need to manage my time a bit better.

I am confident in saying no. Practising on my family has helped.

I do things for me, go out with my girlfriend and choose to do things when my husband is watching sport. I'm even reading a book at the moment.

I have been able to look after myself and get my health on track just by talking to my family and asking for help so that I have time for me.

I take time for me and I recognise I am important, and I need time for me. I have put in place time for me and me and my family.

Putting myself last has changed because I now know that I need to put myself first. My family can deal with their health issues and they are doing this for themselves.

I now understand it's ok to accept help and I do accept help in areas I need. I do for myself what I can and I am open to options and ideas for assistance where I need. My children help around the home more as they now understand my condition better.

I am asking for help realising that I can't wait for help because it won't happen. Now I can leave a note and there is no "tone".

Sessions 5 & 6: Unpacking symptoms

Sessions 5-6 of the training focused on the diagnosed conditions and symptoms. Participants chose eight of their top symptoms that most impacted their life, scored the intensity of the experience of this impact and went through the same process defining where they needed to be (short-term) and what they would like their experience to be. The needs to be provided important way points for measuring the value of treatments, as these became the goals which described what improvement we needed to see. If a product or treatment could not make a measurable impact on any of the goals, then it may have limited value.

We unpacked the lifestyle causes that could trigger or worsen each symptom in order to use this as a basis for researching potential solutions, including what it would take to implement these.

These sessions also skilled participants to do simple research for each of their conditions so that they could understand what the problem was (medical description), cross check the symptoms and tests mentioned in the research and also see the potential complications (future risks) which became the default end point and was often a strong motivator for change.

Part 2: Sessions 7-10

Whereas the first part of the training focused on the experience, or the aspirational end point, which gave meaning to the journey, the second part of the training focused on the medical end point giving participants the skills to navigate their medical journey and make informed decisions.

Throughout the course the model uses the Value Capture logic using defined reference points (As is, Needs to be and To be) against which to measure the progress of the journey (reduction of pain) but also to capture the value of any resource to the journey.

In sessions 8-9 we also use the logic to determine the value of any treatment for a given condition, against specific value criteria which includes the medical end point that is selected by the participant for each condition. This exercise is one that helps the person work out how far a treatment can take them or the odds of a treatment or combination of treatments/lifestyle working for them.

Session 10 was the wrapping up of the training and where we did all the post-course scoring, sharing with each other how far we'd come and discussing the 3 monthly follow-ups.

Session 7: The medical end point

Determining the Medical End Point

Prior to determining the realistic medical end point we undertook the necessary research to make sense of the risks during sessions 5-6 which meant that the following had already been collated for each diagnosed condition:

- the medical problem and potential causes (what's happening and why);
- symptoms associated;
- future health risks (complications); and
- what they could do to help themselves.

Participants were then able to select their realistic medical end point (where do I want to end up) for each of their diagnosed conditions in terms of:

- overall outcome (cure/remission, improvement, stabilisation, slow the progression, or symptom-relief only),
- medical treatment dependency (stay medication free, become medication free, reduce medications, not increase medications, open to increase medications; and
- mitigation of selected future health risks.

The Health Statement

With this information it was relatively easy for each participant to construct their Health Statement which they could use at any appointment (p26). It would illustrate to any medical practitioner that the participant knew what was wrong, what needed fixing, what risks they needed to mitigate, where they wanted to end up and also any criteria they had which would need to be factored in. We also use a Conversational Approach which helps to structure the questions around the risks and the medical end point.

We saw that clarity and simplicity of this method gave the participant the required confidence not only to ask the questions, but to understand the answers. It appears that medical practitioners responded well and positively.

Session 8-9: Working out the value

Determining the value of treatments

Prior to determining the value of treatment, participants were shown how to make sense of their medications which involved internet research (www.drugs.com) to collate the following for each medication:

- what is it for;
- which future health risks will it mitigate;
- side effects; and
- disease interactions

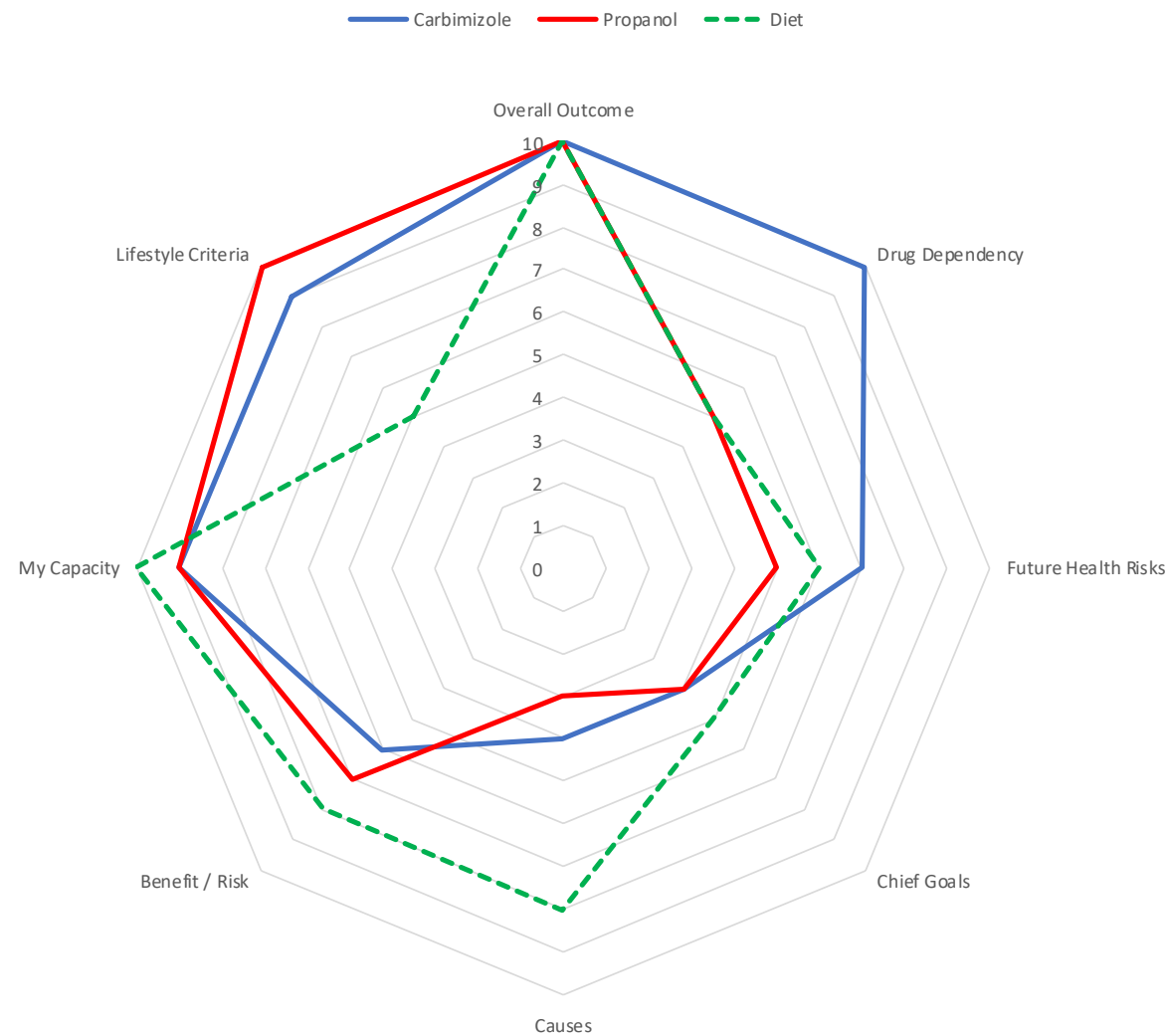
Treatments for a single condition could then be assessed against 8 value criteria for measuring value which included:

- Overall outcome
- Conventional medical dependency
- Future health risks
- Main goals
- Causes/triggers
- Benefit/risk (using the treatment ready reckoner)
- Means (capacity to do a treatment/pathway)
- Lifestyle criteria (willingness to commit to a treatment/pathway).

The two clinching criteria, the means and lifestyle criteria, often determined the overall value where unwillingness to commit or inability to do/follow a program rendered the treatment of no value.

From this small, but concise amount of information participants were able to see how closely a treatment aligned with their medical end point, which goals it would address, how far it could address the causes (triggers), and give a benefit/risk score. Invariably, when the value radar map *Comparing the value of treatments for a single condition* was completed (p53), the positive impact of a specific lifestyle change (diet, exercise) became apparent and, in several cases, was sufficient to motivate change.

Value Radar Map for a Single Condition (Graves)



Some observations

Overcoming resistance to change

The program offered an autonomous process for participants to focus on their desired experience and find solutions that would work for them. It was a non-judgmental platform where no answer was right or wrong, and where solutions aligned to the experience became a means to an end, rather than the end itself. The person moves from *nobody listens to me* towards *I am hearing myself*. This ensured that solution sets and approaches were unique to the individual, their experiences and their set of circumstances.

Solutions that were focused on satisfying the incremental need and were strength-based, or within capacity, stood a greater chance of being implemented and producing results. Similarly, decisions generated through the autonomous process, or choice, are more likely to be implemented than those arrived at through coercion or expectation.

Where there was a fundamental resistance to change [I won't do it] then barriers became no more than excuses, and the process itself created friction that mirrored internal conflict. While many participants were in difficult circumstances where there appeared to be no way forward [I can't do it], some were able to work through this to find solutions and then act on these, but for others the friction generated was sufficient to halt the journey. Although there may have been a strong desire for a better experience in life, resistance to change overruled any potential for solutions. Under these circumstances it may be that change only occurs when one cannot afford not to change.

Health literacy

Most of the participants knew what they should be doing to help themselves, but most were stuck with little confidence or motivation to make change. Although greater health literacy can support health consumer choices it is not a strong motivator for change nor does it, by itself, bring the person to a point of readiness. Most complained of information overload and the struggle to make sense of the information within the context of their case. It served to increase their frustration around who or what could help, leaving some at the "why bother" stage. As one participant put it "you have to know what you need before you can ask for what you need".

By focusing on the key reference points for measuring value, participants were able to know what they needed to achieve, and why, and within what time frames, and were able to seek pre-qualification before making decisions. Some participants, who were struggling to get coherent and meaningful treatment strategies, did observe that members of their healthcare team were unable to either meet their needs or answer their questions satisfactorily which reinforced their own lack of confidence in the system. However, with the skills learned, those having difficulties were able to filter through those healthcare practitioners who couldn't help to find those that could. The added bonus of this newfound capacity to qualify the odds of a chosen plan working for them increased confidence and became a strong motivation for change.

Trust

Some participants had issues with the health system which undermined the capacity to build relationships. Issues ranged from frustration in the amount of time taken arranging appointments and traveling to see multiple specialists, insufficient time at the appointment to discuss their case and options, or an unwillingness to do so; dissatisfactory treatment or inability to get a diagnosis or treatment that worked; and their own distrust or reluctance for prescription medicine as a first line treatment.

In order for participatory health to succeed, a degree of mutual trust has to exist. Trust is ultimately founded on the understanding of what each party can and can't offer. For the health consumer trust is based on verification of how far the health professional can meet their needs, and for the health professional verification that the patient is not driving blind but understands and is addressing their risks.

The Health Commons training equips people to navigate their options and factor in their risks. It leverages the natural inclination for people to determine the odds of a something working for them and allows the health consumer to easily filter through the options based on the pros and cons for their individual case. Through this process, the trainee was able to see how far individual treatments could take them and how a combined treatment approach, that involved lifestyle change, was integral to the overall outcome. Using the Health Commons method, it was possible for participants to express themselves with clarity and have direction in their questioning, and the feedback regarding their experience in collaborating with their health team was positive. The statements reveal the proactive nature of the participants which probably was a key factor in the quality of the responses they received.

"Good response from specialists, they are confident I can monitor how I'm going and how proactive I am being. Test results all improved."

"I know the questions to ask and I can navigate my way and pinpoint more accurately what I need."

"I'm on the right path and heading the right way to have a happy fulfilled life. I feel in control of my destination and not intimidated to ask the right questions."

"I know what I need to do and what to monitor; have referrals; proactive in talking to health professional and I'm driving conversations with my doctor."

"I know the questions to ask and feel better about making informed decisions."

"Feeling good and confident to look after myself knowing that medicine can't help."

"I have been engaging more with my GP and I feel more confident in our appointments."

Participatory Health: Proactive patients

Participatory health: proactive patients

Participatory health requires patients to become proactive in their health journey. Therefore, patient activation is an integral part of the process and needs to offer pathways for informed and shared decision making based on coherent and logical plans that are fully comprehensive from the patient's perspective.

Since the 1970s we have struggled to determine what brings a person to a point of readiness to adopt change. The Transtheoretical Model (Stages of Change) is used as a reference for many research programs.

[This model] focuses on the decision-making of the individual and is a model of intentional change. It operates on the assumption that people do not change behaviors quickly and decisively. Rather, change in behavior, especially habitual behavior, occurs continuously through a cyclical process. The TTM is not a theory but a model; different behavioral theories and constructs can be applied to various stages of the model where they may be most effective.

<https://sphweb.bumc.bu.edu/otlt/MPH-Modules/SB/BehavioralChangeTheories/BehavioralChangeTheories6.html>

10 processes of change are identified, but the limitations of the model when applied to public health, include the following:

- The model ignores the social context in which change occurs
- The lines between the stages can be arbitrary with no set criteria of how to determine a person's stage of change. The questionnaires that have been developed to assign a person to a stage of change are not always standardized or validated.

- There is no clear sense for how much time is needed for each stage, or how long a person can remain in a stage.
- The model assumes that individuals make coherent and logical plans in their decision-making process when this is not always true.

The Health Commons program covers all the 10 processes of change as outlined but, more importantly, it deals with the limitations of the model namely that:

- it embraces the social context in which change occurs (hence we include circumstances as being equal to condition);
- it is highly likely that the results from the data will lead to a development of criteria that determine a person's stage of change;
- we can begin to make clearer sense of what may dictate the amount of time needed or required for each stage; and
- Health Commons, through offering a very robust training and the carefully crafted surveys, can bring participants to coherent and logical plans via the Health Commons decision-making process.

APPENDIX 1

Smart Patient Foundations: Value Capture Methodology

The Smart Patient project uses Stephen Alexander’s Digital Value Capture® methodology as its framework for measuring and validating patient value. This appendix provides as brief history of major milestones and key influences for the development and application of the methodology in Australia.

Digital Value Capture® was influenced by the work of Professor Brian Collins, who argues that all large scale infrastructure project funding is subject to wicked problems. Professor Collins cites a number of contributing dynamics that complicate infrastructure financing including:

- inability to generate sufficient value for each party to overcome resistance to change
- lack of any holistic comprehension of the interconnected environment that infrastructure operates within or is connected to
- inability to leverage the potential synergistic value between multiple types of infrastructure and interrelationships

As the costs of finance rise, Professor Collins notes that pain associated with wicked problems often arises from a lack of holistic design. A digital mesh is required to enable the synergistic value between multiple infrastructure types to achieve the required ROI to justify the investment and generate sufficient personal value to achieve adoption of the associated services. He recommends we move from a consumption-based economic model to a model based on optimisation, collaboration and conservation of resources (while maintaining a competitive profit-based value system).

Stephen Alexander met with Geoff Mulgan in Adelaide in 2010, who confirmed that a model using multi-faceted value criteria is required to predict and then validate whether government policy intended to deliver public value will work. Smart Patient uses the Digital Value Capture®

method to capture data to determine public value policy outcomes — for example, the measurable public value impact of increased wellness, kindness and resilience.

Within the health domain, the primary influence has been Sir Muir Gray — one of the world’s leading healthcare reform experts — who champions the importance of patient-centric value within healthcare systems. During a lecture at the Cochrane UK and Ireland Symposium in 2016 Sir Muir Gray suggested that health systems should send a range of questions to a patient before an appointment to determine what value means to each patient and then use those value outcome criteria to measure the cost and benefit of any treatment. He suggested the first question should be “what’s your problem?” so that during ongoing value monitoring patients can answer follow-up questions like “since your operation, is your problem better or a little better or worse in your subjective experience?”

Sir Muir Gray argues that these kinds of subjective value outcomes for patients would complement existing objective measurement systems to provide a more cost-effective best practice model. As an example, he described this scenario: a surgeon assesses a patient and gets a perfect Oxford knee replacement score, which indicates the surgery would deliver great benefits and a high return on investment. However, if the patient values being able to kneel at prayers or bend down to do the gardening then the surgery will not solve the problem they and their relatives care about (and expected the care giver to fix). Furthermore, given no medical intervention is risk free then the risk-value equation (from a patient perspective) may compel the patient to make lifestyle changes to remedy the problem and use surgery as a last resort, rather than the system defaulting to a surgical procedure regardless of its value or capacity to solve the patients’ problem.

Sue Varden employed the Digital Value Capture® methodology in 1997 to determine what type of public, social, personal and community value Centrelink would have to deliver and what type of organisation it would have to become to achieve its intended policy outcomes over a 10 year journey. Sue stated that in the following 10 years after its adoption, the model had enabled her to predict precisely (“within a millimetre”) where the value outcomes would take Centrelink.

Jane Treadwell — ex-CIO and Business Transformation Director at Centrelink — commented:

“How do we justify an investment in a network of organisations in the same sector (potentially one’s competitors)? Traditional business cases will satisfy the needs for notions of cost savings and return on investment (ROI). But when it comes to understanding and leveraging the value that comes from a network of operators working together, traditional methods are no longer applicable or useful. Stephen’s value methodology solves that problem and also indicates where the project and the enterprise will arrive through the creation and use of digital value.”

Jane Halton used the methodology in 2004 within the Australian Department of Health and Ageing to determine the potential value of emerging digital-enabled health consumers and patients to those who pay for health services (both insurance and public sector funders). She wanted to better understand the dynamics between this emerging health consumer force, whose aggregated power would at some point influence both policy and practice, and those who have the legal right to manufacture/dispense and diagnose/prescribe.

APPENDIX 2

NHS Triple Value Agenda

Much has happened in the last three years within health services: the accelerated impact of the Human Genome Project is but one example. But the most significant changes have taken place outside the service. Chief among them is the increase in citizen and patient interest and influence, through the spread of the smartphone in all countries – rich and poor alike.

The other huge external factor has been the continued economic problems in most countries. Even where investment in healthcare is increasing, it is not rising fast enough to meet need and demand. Healthcare is facing a huge challenge and our focus needs to shift to value – but there are three different types.

1. Allocative value

The first we call ‘allocative value’. Have we allocated resources to different groups equitably and in a way that maximises value for the whole population?

Groups could be defined either by clinical condition, such as cancer, mental health or respiratory disease, or by a characteristic, such as having multiple morbidity and frailty. These groupings can be called programmes.

Once resources have been allocated to programmes, it becomes the responsibility of those who manage services – many of whom are clinicians – to carry out further allocation within the programme budget. So, for example, allocating resources to asthma or chronic obstructive pulmonary disease (COPD), or sleep apnoea, within a respiratory programme budget.

Furthermore, once money has been allocated within the respiratory budget to, for example, COPD, the clinicians and patients need to get together to work out the best value through the right distribution of resources into prevention, diagnosis, treatment, rehabilitation, and long-term support for each system, using the STAR tool.

2. Technical value

Work to improve the quality and safety of healthcare obviously increases the value derived from resources allocated to a particular service. Don Berwick, a renowned international expert on patient safety, gave an impassioned speech about the ethical imperative to tackle waste in healthcare. But this is only one type of value – technical. There are two other types of particular interest.

3. Personalised value

The third is personalised value. We need to ensure that decisions are based on the best current evidence, a careful assessment of an individual’s clinical condition, and an individual’s values. These are the values they place on good and bad outcomes, because even the highest quality healthcare can do harm.

These are the three types of value we need to focus on in the 21st century.

Smart Patient takes a unique stance with regard to digital governance that exceeds current consumer expectations regarding privacy, security and safety. Our approach may therefore contribute to building more consumer trust in digital health.

<https://www.nhsconfed.org/blog/2015/05/the-triple-value-agenda-should-be-our-focus-for-this-century>

APPENDIX 3

Digital Health Governance

The approach rests on the notion that a person owns the Intellectual Property (IP) of their person, in much the same way that they own their own body and can exercise certain rights accordingly. Smart Patient therefore attributes data created by the individual about themselves and the analytics they generate to that individual, making no claim of ownership or rights over that data.

Over time, Smart Patient intends to assist individuals to claim this data as private IP. The individual may in turn then grant conditional consent via a digital smart contract for any party to use their data for specific purposes. Those parties could include care givers, Metro South Health Service, common interest groups, research groups and/or Smart Patient as a custodian for the common good.

In the Metro South context, this could provide MSH with raw data (for use in its own analytics) as well as intelligent analytics generated by the Health Commons apps. In this scenario, MSH would derive additional value through dynamic reporting about customer experiences of its own service delivery within the context of a hospital without walls, as well as the value impact data describing what set of resources each person used to better manage the impact of their chronic disease.

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Youth and Family Services: Building independence and Participation

Multilink Community Services: Challenging Boundaries Together

ADRA: Community Care Centre, Logan Central. Emergency relief and assistance

Regional Development Australia, Logan and Redlands

Diggers Services Club, Logan. Membership support

Desley Scott & Kathryn Alexander were invited to speak at Myriad by Murray Galbraith the organiser of Queensland Government's Advance Queensland initiative 2018 Myriad festival celebrating creativity and innovation.

Desley was underscoring the use of blockchain technology in the Health Commons initiative to enable people to own their own data and then grant its use for the common good as a best practice model for governments around the world.

Greg Moran, AIDH, for his continued support and probono activities centred around the financial gap impacting health consumers, and how to cross-match patient-centric data with system-centric data classifications.

E&Y provided probono advice on the potential social impact, social enterprise structures and the potential value of addressing absenteeism and presenteeism. **Tam Shepherd** presented this project to the Australian government as an exemplar in digital governance where the individual could control and own the rights to the data they generate via the use of Blockchain smart contracts.

Professor Daniel Pérez Vidal, of the Hult International Business School, London campus, and his students undertook a market research and provided advice on how to take this initiative to a global market.

If resolving a health issue isn't key to getting us to where we want to be, then we will not adopt solutions to support this.

Kathryn Alexander

Founder Health Commons Connect

Results and key findings

Title: To determine the increase in pro-activity in people with a wide range of medical conditions following the Health Commons/Smart Patient participatory methodology.

Aim: to discover the preconditions required for readiness to undertake a health journey; to determine the impact of change in sentiment, motivation and confidence on patient pro-activity, and to correlate any findings with increased health outcomes, and to discover what resources were of most value to the journey.

After collating the results at the end of the 12 months program we were interested to see how many of the participants had maintained their motivation, how many were reaping the health benefits, and how their lives had unfolded. Importantly, we were keen to discover whether they were able to engage meaningfully with their health professionals and whether this had this had facilitated their journey.

Measuring the experience was the core outcome measure where we were seeking to determine the impact of change in sentiment on motivation, confidence, patient pro-activity and to correlate any findings with increased health outcomes.

Did the program work? Did people develop sufficient skills to help keep them on track? Did they become Smart Patients and get better health outcomes?

The patient narrative

The path and the solutions patients choose are determined by what matters to them. From the research we saw that solutions that were the most attractive were those that could meet their needs. However, resolving a health issue may or may not be a core need. Invariably, if a person can get by and manage their condition so that it doesn't interfere with them getting on with their lives, then fixing this will be low on the agenda, regardless of where that health issue could ultimately take them.

A patient's scenario, or the reason that they visit a doctor, is because of a negative impact on their lives which is creating sufficient friction to seek help. This friction will impact the patient's experience or sentiment. We found that it is the sentiment that drives the journey, drives decision-making and the motivation, and that solutions that reduce the intensity of that sentiment are favoured over those that offer no immediate benefit or bear no relationship to that sentiment.

We found in many cases that the patient's journey is not predicated on fixing a health issue. When unpacking the journey, each participant described where they are now and their current sentiment, and where they want to get to and their future sentiment. We found that what aligned the starting point to the end point, and also defined the means (or the choices made) was the core sentiment. So unless resolving the health issue is pivotal to this then we found that solutions that reduced the impact of the core sentiment were selected over those that could improve health.

Case no 2 is a clear example of this. Sonja is a 23 year old young woman with rheumatoid arthritis. Firstly, we captured the impact of this on her life and her sentiment:

I never know when my condition's going to flare up. I don't feel like I have control over my condition and others see me as my condition. I feel worried and discouraged about my future. I've lost motivation.

People see me as my condition. I've lost motivation.....

I've realised that my goals and future aren't defined by my condition. Now I live my life instead of dwelling on it.

The sentiment she described was one of *hopelessness*. Then we asked her where she wanted to be and how it would make her feel:

To have direction and purpose in a job or role that I would love. This would make me feel free and independent.

The sentiment at the starting point is one of hopelessness and at the end point is one of *freedom* and independence. Sonja does not reference her health in her end point, but rather getting a job. So there is no obvious health pathway between her starting point and the end point, unless she believed that changing her health would deliver her better chances of employment.

This is borne out in the impact of health as a barrier to the journey, or Sonya's capacity to move forward, where we saw that her health issue was not a barrier in itself:

My RA doesn't bother me much, it's more how people see me and what I can and can't do. I feel like I'm being judged unfairly which is frustrating. It impacts my confidence and motivation.

And when asked where she wanted to be she said:

*Feeling free to do whatever I want to do;
to be seen for who I am and not my condition.
To be recognised for what I can do.*

It becomes apparent that solutions that could have the most value, and therefore seen as worthwhile, will be those that help Sonja to be seen differently by others. The overriding sentiment is to be of *worth*. The most meaningful solutions would include exploring her talents and becoming work ready, and not necessarily dealing with the rheumatoid arthritis. Solutions that would be most attractive would address her key concerns which could transform the sentiment of hopelessness to one of self-worth:

*Worried that health condition will limit job prospects.
Fear of not being seen as worthy of contribution.*

As we followed Sonja on her journey, we did indeed confirm this. At the end of the 12 months her descriptions of where she is right now in relation to where she was 12 months previously reveal that no changes have been achieved in relation to her physical health, but the solutions she put in place have been instrumental in getting her to her end point: to have purpose and direction and for people to see her for what she can do.

During that 12 months she volunteered more responsibilities at work to show others what she was capable of, she finished her traineeship, and she is now job ready. Not only this, she has savings and can buy a car. Her health is

no longer an issue in terms of it dictating how others see her.

From a clinical perspective we may appreciate that while her rheumatoid arthritis may still be active and relapsing, that the risk for future depression has been averted. In one of her summing up statements around her improvements in health she says:

I feel a lot stronger, physically, mentally and emotionally. Keeping busy, less stress and I have more opportunities at work, which makes me feel like I can do anything. I don't think about my condition now and I don't think it limits me when it comes to work.

Case 2

	GENERAL HEALTH CAPACITY (impact on getting on with life) AS IS, TO BE and 12 mo	HEALTH ISSUES (impact as a barrier for the journey) AS IS, TO BE and 12 mo
2	<p>I never know when my condition's going to flare up. I don't feel like I have control over my condition and others see me as my condition. I feel worried about my future and discouraged about my future. I've lost motivation.</p> <p>To have direction and purpose in a job or role that I would love. This would make me feel free and independent.</p> <p>I am not as worried about my condition anymore and it has made me focus on other things.</p>	<p>My RA doesn't bother me much, it's more how people see me and what I can and can't do. I feel like I'm being judged unfairly which is frustrating. It impacts my confidence and motivation.</p> <p>Feeling free to do whatever I want to do; to be seen for who I am and not my condition. To be recognised for what I can do.</p> <p>It's the opposite now. Everyone sees me for what I can do. I have proven myself and when I mention my condition, they are shocked.</p>

“ [The training] helped me to process my thoughts and feelings a lot better. I feel like I have more clarity and more direction. I feel like I can move forward in my life instead of being stuck in one place. I realise that my goals and future aren't affected by my condition so much, so I don't worry about this.

Readiness

“ I hadn't considered this before..... now I know I am ready.

Many of the participants were at a similar point in their lives as Sonja, not yet ready to take control of their health journey. When the health issue does not significantly impact one's life or hinder the journey, then we don't look for solutions to fix that health problem. This, I suspect, accounted for the some of the drop out.

However, fifty percent (16/31) did complete the program and from these some participants were closer to a point of readiness in dealing with their health issues whereas others were further away but still eager to address other impacts on their lives that were causing friction and inhibiting their ability to move forward, including with their health. The core sentiment for many was feeling *overwhelmed* and *pressured*, and as the program encouraged participants to find solutions to alleviate those pressures and friction, then it became apparent that this could, in turn, bring the person to a point of readiness and facilitate the health journey. We saw that if solutions could not be found to reduce the current friction, then the health journey was unlikely to begin.

Alanna, case 11, was at a point of readiness. She was suffering from multiple problems including fibromyalgia, joint hyper-mobility syndrome, miscellaneous connective tissue disorder, anxiety, overweight and bulimia. Resolution of her health condition was pivotal to achieving her end point. Both her general health capacity and her health issues statements reflected this by referring to specific health improvements that she needed to achieve (ease of mobility and holistic pain management). Her key concerns were being *emotionally and physically trapped with a con-*

dition that was only going to get worse and her sentiment was feeling *hopeless* and *defective*.

The key hurdles to moving forward were pain and exhaustion from the condition itself, affordability of treatment, insufficient support and difficulty in trusting others. This last hurdle was based on the fact that she had been unable to get a definitive diagnosis, treatment had been based on *try this and see* and nothing was working. As a consequence she was going backwards requiring higher and higher doses of pain management medications. Hence one of her aspirations was to be in charge and knowledgeable about her condition.

The preconditions existed for readiness as resolving the health issue was pivotal to the journey. But unless solutions could be found that would address the sentiment and untrap her from her condition, then that point of readiness could come and go.

The program enabled Alanna to view her position through a wider lens where she was able to bring into focus and consider things that hadn't been apparent before that could have value in changing the sentiment and take her to her desired end point, to be *in charge* and *peaceful*.

As we followed Alanna over the 12 months we tracked her progress and how she started to take back control and self-determine her own pathway which included pre-qualifying and finding the right practitioners and building a health team around her that was focused on her outcome, or what she wanted to achieve.

	GENERAL HEALTH CAPACITY (impact on getting on with life) AS IS, TO BE and 12 mo	HEALTH ISSUES (impact as a barrier for the journey) AS IS, TO BE and 12 mo
11	<p>I am in pain from my joints and recurrent dislocations. I have disabling migraines and fatigue. My motivation and sense of optimism leaves me feeling hopeless. I can't work, and I am not the best partner one could be.</p> <p>To be in charge and knowledgeable about my condition with more ease of mobility.</p> <p>Different to what I thought. I have accepted that things may never be as easy as I want them to be, but I am aware of my limits and feeling stronger.</p> <p>(As is score 9/10; end score 4/10; 50% change)</p>	<p>Because I get immobilised by pain I spend all my energy getting through the day and nothing left over for self-care.</p> <p>To be peaceful and have more holistic pain management</p> <p>This week for the first time in 3 years I haven't required any pain medication. I am finding some joy in movement now, I know the exercises that don't cause pain or injury.</p> <p>(As is score 8/10; end score 3/10; 50% change)</p>

For Alanna, as with most of the participants, it was incremental change that powered the journey. Readiness is predicated on whether the solution offered is sufficient to make a difference (reduce the impact of the sentiment) and that the effort required is within capacity, and therefore worth it. When faced with insurmountable hurdles and coming from a place of moving in the dark, then a step by step approach that confirms the direction at incremental stages is sufficient to fuel self-motivation.

I have been able to make incremental choices and changes by letting go of an 'all or none' mentality and instead focusing on what are the options available to me, and how they fit with my priorities.

Alanna 's capacity to take back control lay in the clarity of direction she achieved and bringing in solutions that would help address the many and varied difficulties she was experiencing, including work and family issues.

The skills she learned using the Ready Reckoner part of the program assisted with the navigation of the health journey and enabled her to take back control and ultimately find the peace she desired.

This part of the program allows people to match practitioners and treatments against the medical improvements they wish to achieve and where they ultimately want to end up. Through simple research for each condition and treatment used we can determine the key journey reference points and generate simple surveys that can show how much a practitioner or treatment is aligned with where we want to go. Knowing how far a practitioner could take her and what risks they could mitigate enabled Alanna to rapidly filter any practitioner or treatment that had little to no value from the equation.

Monitoring

In monitoring the journey we measured percentage change from three reference points: the percentage change in impact of sentiment, motivation and confidence.

- ▶ Sentiment: what drives the journey
- ▶ Motivation: what sustains the journey
- ▶ Confidence: predicting the journey

Sentiment

There was a 60% change in impact in sentiment (8/10 - 2/10) over the 12 month period as Alanna moved from hopeless and defective towards peace.

Motivation

There was a 50% change in motivation (4/10 - 9/10). We see how the transformation of sentiment regenerates the self-motivation required to sustain the journey:

I was validated and learned that I don't need perfection or to be completely cured in order to progress. This helped me overcome a lot of psychological barriers and look for incremental change instead of one thing that would 'fix' me.

I have cultivated more of an identity outside of my illnesses and have financial and personal breathing room. I am less beholden to my illnesses to define me and the way my life is going to go.

Confidence

There was a 40% change in confidence (4/10 - 8/10) where we measure confidence against our capacity to work out the odds, or predict the outcome of any health decision:

I don't hand over my wellbeing to specialists any more. I was able to let go of a lot of expensive adjunct treatments that weren't serving me. I am far more in the driver's seat feel like I am the expert in my own life rather than deferring to others. I have a team around me who listen and care about my ideas.

Proactive status

We did not score the proactive status, but we did capture statements that reflected what their pro-activity looked like and what it meant to them.

I have much better capacity to manage my health and I can see that self-care is an investment not self-indulgence. I have gotten rid of that self-doubt voice. I don't compare myself to others. I feel like I know what works for me and a plant based diet has been surprisingly helpful in maintaining energy levels.

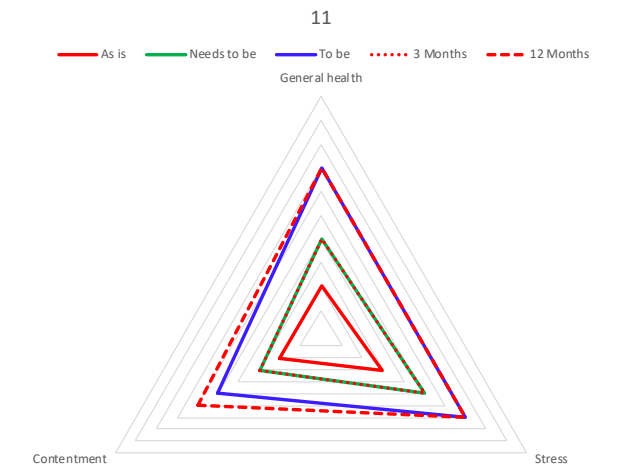
Health status

We did not score the overall health status but we did measure health progress using radar maps that showed improvement in symptoms (below) and in general health capacity (aspirational end point radar map). Alanna's summing up statement, only after a year of embarking on this journey, surprised us all.

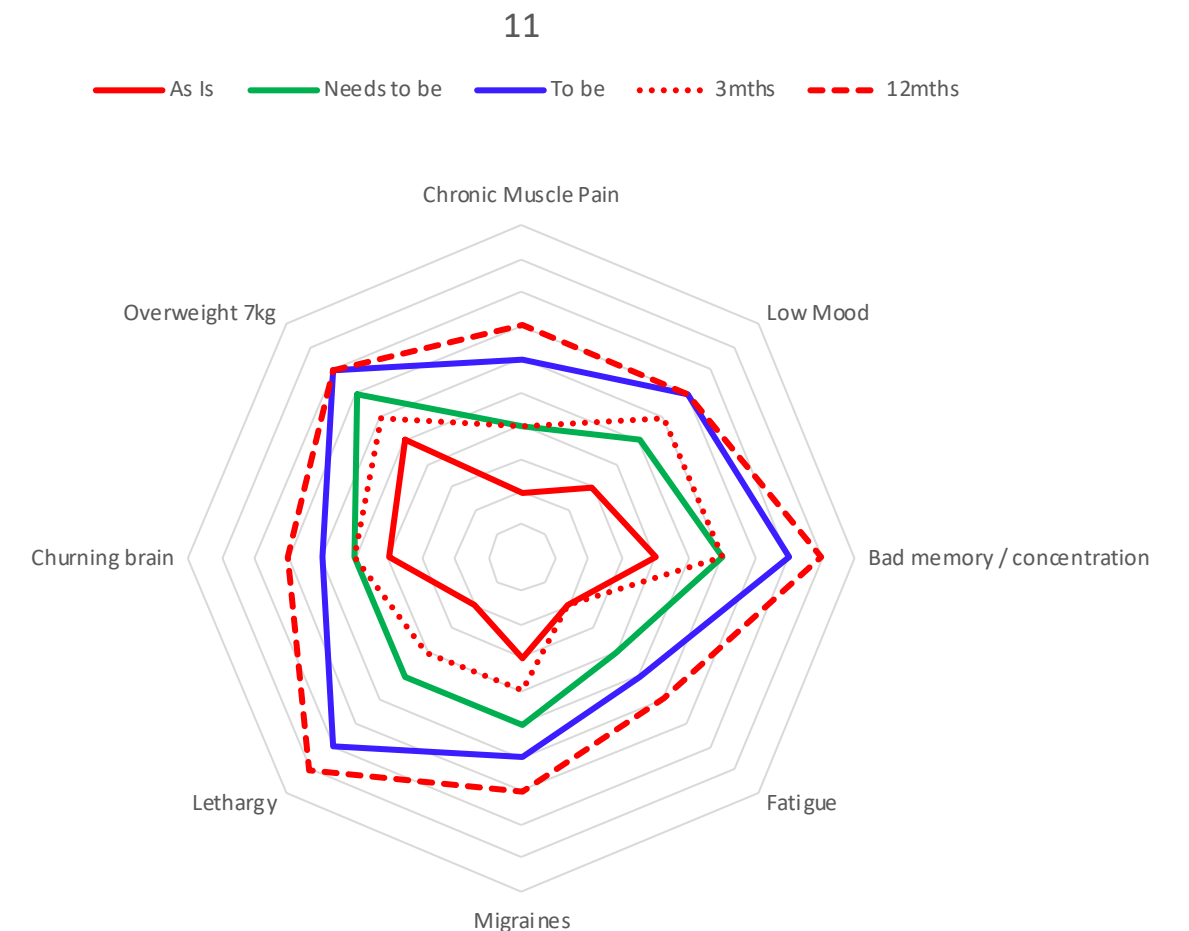
My symptoms have eased and I am not worried now. Everything I am doing seems to be working, but if I have a flare again I feel that I know who to go to, to help me.

This week for the first time in 3 years I haven't required any pain medication. I am finding some joy in movement now, I know the exercises that don't cause pain or injury.

Aspirational end point radar map



Symptoms radar map



The core sentiment drives the patient journey. When the impact of circumstances outweighs the impact of health, then health solutions will be low on the agenda.

Kathryn Alexander

Founder Health Commons Connect

Results

“ Things are generally not worth the effort unless we can see how they will really help. ”

Title: To determine the increase in pro-activity in people with a wide range of medical conditions following the Health Commons/Smart Patient participatory methodology.

Aim: to discover the preconditions required for readiness to undertake a health journey; to determine the impact of change in sentiment, motivation and confidence on patient pro-activity and to correlate any findings with increased health outcomes, and to discover what resources were of most value to the journey.

Cohort: n=31, 6 male, 25 female, average age 46 years (range: 23 - 69 years), with one or more chronic conditions. Participants had to want to be in a better place, health-wise, than they were currently heading and have sufficient capacity to make change.

Methods

Participants consented to attend a 10 week training and to be assessed during and immediately after the training, and at 6 months, 9 months and 12 months.

Primary objective measures

- ▶ Percentage of people who completed the program;
- ▶ Percentage of people who reduced their medications;
- ▶ Percentage change in motivation;
- ▶ Percentage change in confidence; and
- ▶ Percentage change in sentiment.

Statistics

Percentage of people who completed the program:

- ▶ 50% completed the program to the 12 month mark. (16/31)
- ▶ 61% completed to the end of the 10 week training (19/31).

There were two study groups. There was a 15% drop out from the first study group (3/19) and a 58% drop out from

the second study group (7/12). The second study group went online due to COVID.

Percentage of people who reduced their medications:

- ▶ 56% (9/16)

Percentage change in sentiment, the average reduction in the magnitude of impact:

- ▶ 53% (range 30%-90%)

Percentage change in motivation, the average increase:

- ▶ 42% (range 30%-90%)

Percentage change in confidence, the average increase:

- ▶ 50% (range 20%-80%)

Conclusions

There was an inverse relationship between the reduction in impact of core sentiment and increase in motivation and confidence, indicating that solutions that reduced the impact of the core sentiment had a positive impact on motivation and confidence which would self-perpetuate the journey. Better health outcomes also correlated with these findings, with the most notable results on mental health.

The nature of the training enabled participants to arrive at their own conclusions where they could self-determine their journeys choosing solutions that would offer the most value in reducing the core burden. No advice or recommendations were given during the training. All participants that completed the program were proactive to a greater or lesser extent. As pro-activity is predicated upon lifestyle change, most participants adopted sustainable changes that could be easily integrated into their existing lifestyle. These changes were within capacity and had to show sufficient merit to support the effort required. Solutions of high value were those that could address one or more root cause problems and were therefore pivotal to success.

Resources

There were surprisingly few resources that were of value to the journey. Most needs were fulfilled through seeking the appropriate support, and greater self-organisation also played a key role. Most participants adopted exercise solutions that fitted in with their routine, and facilitated diet changes through engaging family support or switching to more healthy home delivery options.

Resources of most value were those that addressed time and space. This covered solutions for support, routine, and time saving on tasks, such as shopping and cooking. Having space within which to satisfy one's own needs/outlets was also an important consideration.

Support

In the home/at work: As time was a limiting factor then delegating tasks, either in the home or at work, was a big consideration in facilitating the journey. Many participants negotiated time out as a social/personal outlet.

Professional: All participants placed a high value on having a team of practitioners that trusted and supported them; and many placed a high value on medications and treatments.

Agencies that were identified of value were those offering Aged Care packages and Youth and Family Services.

There was unanimous feedback from the group on the value impact of support. Through its very nature participants reaped the benefits of improved communication/connection, understanding, acknowledgment, self-expression and harmony with family, friends and in the workplace.

Family support rated as the most valuable resource, both in terms of reduction in personal friction/facilitating the journey and the value impact of having greater connection through better relationships.

Routine

Most participants reported that greater organisation, routine and prioritisation created the space to facilitate changes, especially where time was a factor or procrastination was a problem. Lifestyle solutions that could be easily integrated into the existing lifestyle had more chance of success, such as involving family members in the new routine or doing exercise at home or walking daily instead of signing up for a gym or undertaking a new type of exercise activity.

Time saving on cooking and shopping such as home food delivery options were also a valuable resource, with Hello Fresh chosen by several as a healthy alternative.

Space

All work and no play.....

Most participants took steps to organise time out, time away and family activities. Enjoyable past-times of sharing and laughter, and meeting one's own needs were deemed as essential and of high value to reduce stress and positively change mind-set.

Other

Social media groups / online communities of common interest for health conditions played a very minor role having a somewhat negative impact on motivation.

After the 12 months monitoring participants were asked if their financial costs on health had increased during the period. Fifty-six percent of participants had reduced their medications and a few had reduced their costs. One participant with health issues decided to get a diagnosis during the course and was subsequently diagnosed with type 2 diabetes. She reported an increase in cost due to the new diagnosis. For most people the costs remained the same, and a few had shifted costs away from conventional to alternative treatments. Some indicated substantial savings.

All participants indicated marked improvement in mental health/outlook as indicated through sentiment scorings (facing page). There were no other financial costs associated with improved wellbeing.

It has given me orientation of sorting out the smaller problems and working from there instead of the big picture which is too overwhelming – sometimes all I need to do is ask.

Key observations

Sentiment

Each participant unpacked many feelings and experiences, but the core sentiment is the overall experience contextual to the impact of their health and circumstances on their lives. We observed that the core sentiment was the key driver for the journey; it impacted all decision-making focusing any adopted solutions on how far they could reduce the impact of that sentiment. We found that solutions were selected not on the perceived benefits, but rather on their capacity to reduce this impact.

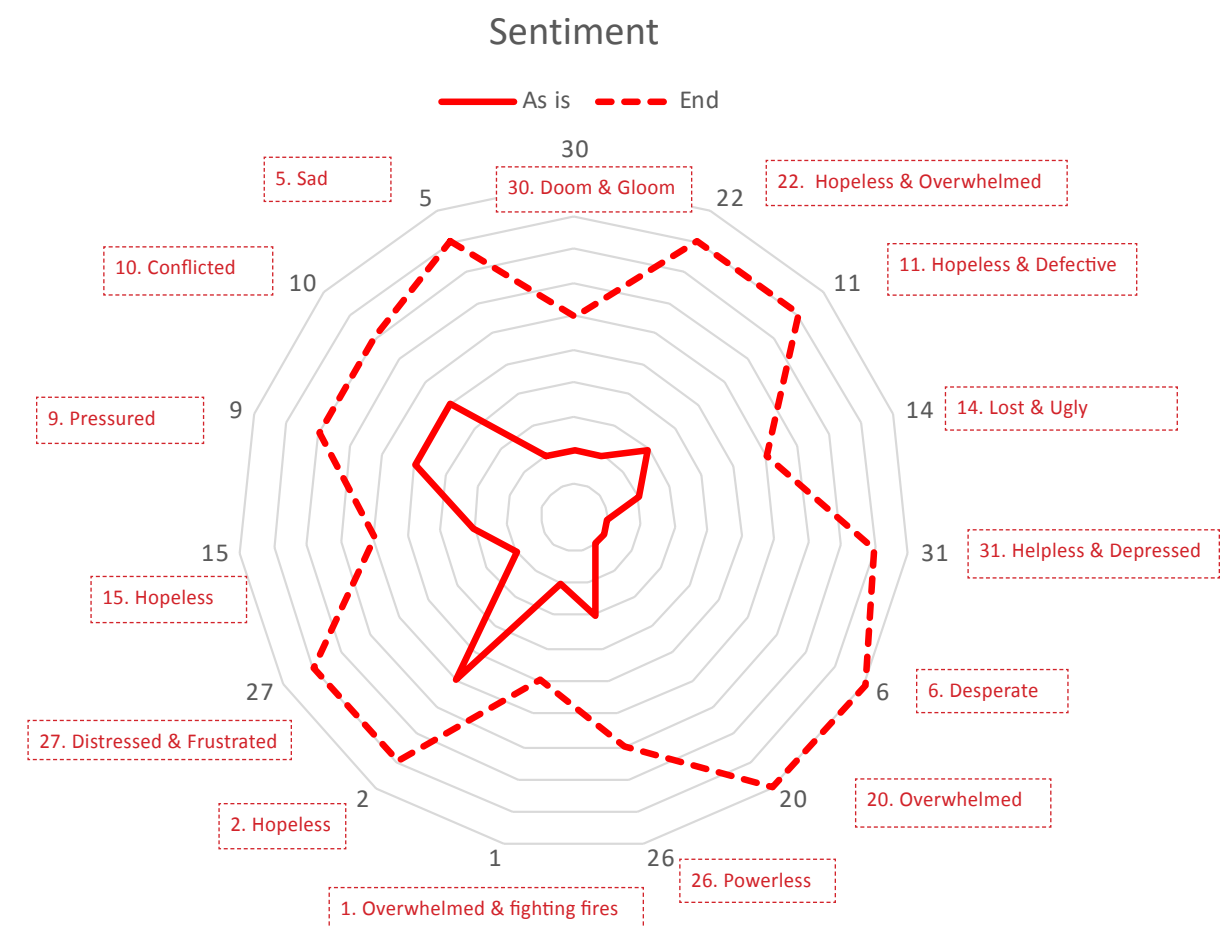
*My life is in tatters, I don't know what to do.
(helpless & depressed)*

Looking back, my life is a total turnaround. I am making positive change and my journey has started.

*Life isn't perfect but nothing is causing me issues.
I have no more depression or anxiety.*

We found that participants naturally sought an holistic approach and were able to identify a range of solutions to meet their needs. Within the context of an approach that factored in their full circumstances, it was possible for participants to see where each solution fitted and its value to the whole, which may never have been realised without a plan. The worth of a solution, or combination of, was tagged to how far it could reduce the impact of the core sentiment. Those that hit the sweet spot had a greater likelihood of being adopted.

Group Radar Map : Reduction in impact of sentiment



Motivation and willingness

Can I make the impossible, possible?

We were keen to discover whether motivation or self-determination would drop off after the ten week attendance /online training. As the radar map illustrates motivation not only continued but doubled.

Most commonly reflected by the group was the impact of incremental change bearing incremental rewards. This increased self-motivation and willingness to continue to make change, as the journey became easier with less friction.

Key learning was that solutions that required less effort and were easily integrated into lifestyle change, and would reduce the impact of the core sentiment (be worthwhile) stimulated greater willingness or proactivity, and were sustainable. These solutions encouraged incremental change which drove the momentum:

I am adding more incremental change and making this a habit - so my momentum is continuing.

We found that having identified what was needed, the most common solution of asking for what was needed and receiving this was sufficient to unlock the journey and make it possible. Asking for and receiving help was a key barrier for many.

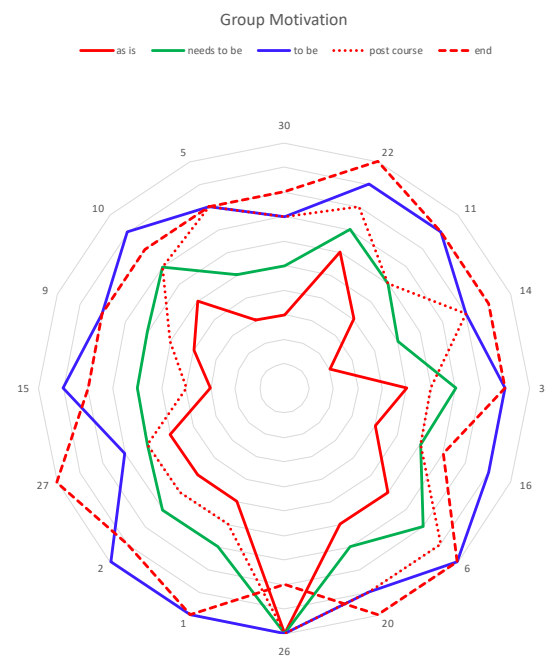
I just changed my lifestyle and am just doing it. I have reduced the time pressure by asking for and accepting help and I am good at saying No now.

Accepting help has been the most pivotal and it's freed me to do the things I want to do.

I'm OK to not be perfect or win the mother of the year award.

Peace and harmony through adding my family into my life and leaning on them when needed.

I feel good, I can cope and put in place things for me.



I am not caught up on the end goal anymore. I am more in the moment and focused on the immediate goals at hand which makes me feel it is more manageable, which helps keep me motivated.

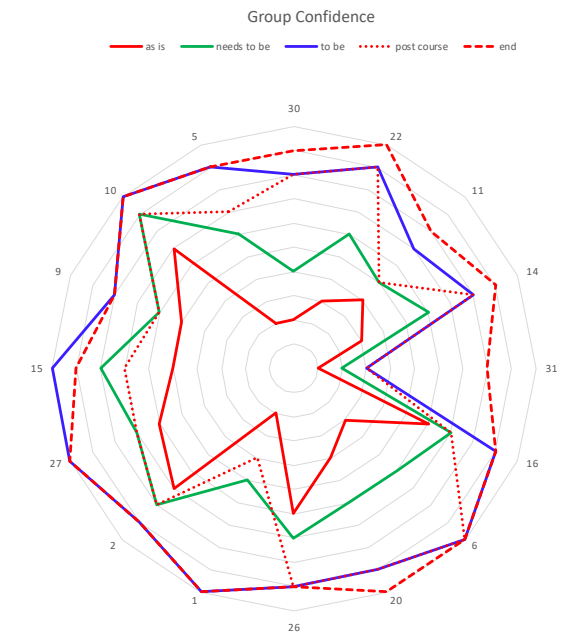
Confidence

How lost am I?

Again, we were interested to see whether confidence continued to increase during the 12 month monitoring period. Similar results were seen as for increase in motivation, more than doubling. The biggest challenge was a lack of trust: a lack of trust in their own capacity to make informed decisions that could take them to where they wanted to be and a lack of trust in their health care provider to make the best decisions on their behalf. Their sentiments ranged from feeling lost, anxious, afraid and despairing to being stressed, frustrated and angry. This led to the overwhelming stance of distrust of the system and a reluctance to engage.

By the 12 month mark the position had changed. The two statements below reflect the common experience by the group.

I don't have to feel anxious about my condition anymore because I know how to get help and where to go for more information and just being informed has allowed me to feel more relaxed. I am no longer lost. I am able to deal with health questions really quickly and with ease.



I no longer have to ignore my health issues as I can talk to my GP and know what to ask. Before I was discouraged with treatment, overwhelmed and distrustful of doctors.

Engagement

Will they listen to me?

From the research we observed that the difficulties in engagement lay in lack of confidence - feeling lost and not knowing what to ask, being nervous or distrustful of the doctor, being afraid to seek help, and fear of being pressured to make poorly informed decisions.

At the end of the program all participants, bar one, were able to engage meaningfully with their doctor or health care specialist. We observed that participants had moved from a stance of *What do I expect of you* towards *What do I need from you?* This was a unanimous finding.

Each participant was actively using the Health Commons/ Smart Patient logic to determine what they needed to know and then rapidly filter through the options. As the logic is heavily invested in mitigating risk, this allowed for trust to develop between the parties.

I can always get what I need and my GP is fab - he now asks me what I want. My relationship with him is better and he actually listens to me and he knows what I'm talking about and he trusts my judgment.

Many reported a reduction in fear and anxiety associated with engagement and went on to develop pro-active relationships with their health team.

I'm not so afraid to seek help now as I would much rather be informed. I have seen all the specialists now and I am working with all of them.

I know I'm on the right track. Because I have knowledge I won't just go and listen or do what they say because I know what I need now. It's been a really great journey. I can communicate with my doctor so am able to go in the right direction regarding treatment.

Readiness

Will I adopt this solution?

We were also keen to discover what behaviours and attitudes underpinned readiness to become proactive, or at what point did a person have to be in time and space to adopt the solution.

The research showed that everyone who completed the program became proactive, so if they weren't at a point of readiness at the beginning of the training, they became so by the end.

Reading through the research we narrowed our attention to focus on *What makes a person ready to adopt a solution*. This shifted the focus from *what's stopping me* to *what will work for me*.

We found that a mix of influences impacted readiness: how great the need was (where was the friction and how intense), how much effort would be required (how hard was it to fix), and whether the solution would reduce the friction sufficiently to make a difference (was it worth it).

It becomes a simple equation of whether the need warrants the effort, and whether the effort is worthwhile.

We were able to see from the research the positive impact of incremental change on driving self-motivation.

It became apparent that a solution-set that could spread the load and reduce the effort was more likely to be adopted than solutions that were focused on the end point, which may increase the friction, require more effort or be seen as unattainable.

Participants were encouraged to find solutions that could get them to their *Needs to be* which reflected their first step or *what do I need to happen in the first instance that would help me on my journey?* We found this to be the pivotal step in unlocking the journey.

We also observed that solutions that alleviated the core sentiment were chosen over those that could not relieve the impact of the core sentiment. Although those solution may deliver some benefit they were unlikely to be deemed worthwhile and may, by default, generate more friction.

$$\frac{\text{Need}}{\text{Effort}} = \text{Worthwhile} \\ \text{(Value impact of solution-set)}$$

Making change

Key obstacles for change

from the health consumer's perspective

From the research we found that the willingness to make change was negatively impacted by the health consumer's stance towards the health system, where there was an expectation towards the system to provide solutions that would work for them. This stance also shaped the patient/practitioner relationship.

This position was further compounded by an unwillingness to adopt any lifestyle solutions that were seen to add to their existing burden of their circumstances.

However, the key obstacle for change in participants who did not adopt lifestyle changes to support their health was the low value they placed on health in the overall scheme of things, so any solutions to improve health were of low priority.

Below are the key obstacles for change that we drew from the data.

Within comfort zone

From the research we saw that unless physical health was impacting the mental or emotional life, or was physically disabling, then there was a reduced need to address it and a correspondingly lower appetite to make any effort.

I feel too comfortable where I am and it's stopping me from doing better.....

Those participants who did adopt lifestyle solutions were those whose health was impacting their lives severely enough, and/or where they had come to terms with the limitations of treatments offered and what this could mean to them should they not change. However, we still saw a tendency to pursue conventional alternatives over making lifestyle changes.

I realised how [poor] the medical system is and how little they do for me. It made me realise that the help is worthless, and no one is going to help you unless you help yourself.

For one participant, a key motivator behind her lifestyle changes was that she didn't want to be a burden on her partner, but these types of statements were the exception.

I am embarrassed and feel self-conscious about my weight. It stops me from enjoying life and doing things. My knees ache and I tire easily. I feel concerned that I am stopping my partner from doing things.

External stressors

All our participants had competing influences with relatively high stress levels. We saw under these circumstances that resolving other issues took precedence over health care. Having sufficient time and space was a big factor, as most were in full time work and with family responsibilities.

Without the initial analysis of what caused the issues I wouldn't have got rid of my son. My health issues were secondary.

Expectations

Generally there was an expectation that the health system would manage and fund health, and so there was little self-expectation to do so. There was a belief that managing the risk of chronic disease was within the doctor's domain. Most participants equated improved results as a consequence of treatment as enough, in itself.

Lifestyle change does not make much difference

Most participants knew that they should be making lifestyle change but they were also of the view that this would not make a significant impact and therefore may not be worth the effort.

For conditions outside the metabolic syndrome/diabetes/high cholesterol/obesity, there was little encouragement to make lifestyle or diet change as there was no evidence to support that it could make a difference. So there was

little impetus to go down this route. Participants reported that their doctors only encouraged their own treatment options and were relatively disinterested in other approaches. This fuels a heavy reliance on the health system.

Health is not sacrosanct

Being in good health was not seen as a foundational requirement for a good life, and therefore it had little value. Two of the younger participants had autoimmune conditions and they reported that there was little family concern for their condition and no offer to support any lifestyle change that may have led to improvements. It may be that there is generally less attention to healthy lifestyles when raising children. A few people on the training were concerned about the health of their children but had taken no steps to address this. However during the

training they reported that instead of eating MacDonald's they were ordering Hello Fresh and choosing the healthy options. They also said that their families were enjoying the food.

Additionally, some felt that self-care was a luxury.

Poor relations with health professionals

There was a significant level of distrust of the health system, anxiety about being pressured into treatment options, and resistance to the paternalistic stance. Several participants were fearful about their conditions and resistant to visiting their doctors. They were afraid to seek help and they didn't know what to ask or how to make a decision. It was easier to leave it.

What empowers a person to make change?

Being in charge

Following the 12 month program the overwhelming sentiment regarding the health journey was that all participants felt in charge, in control and able to make informed decisions, and they had all moved forward, with ease.

We didn't set out to educate or give better health literacy, or persuade people down a pathway of change, but we gave them the opportunity to self-determine their own journey based upon where it was that they wanted to end up. Most participants had sufficient basic knowledge so it was a process of collating this into a journey framework (starting point, end point and default end point) and then being able to use these reference points to measure the value of solutions on their journey. Solutions included any resources, medical, alternative, lifestyle change and support.

The research indicated that many participants went from feeling *lost* and *afraid* to being *relieved* and *relaxed*. The Ready Reckoner section of the training was able to facilitate this part of the journey through creating a template from which to ask questions and measure the value of any recommendations. This reduced the friction of being lost and invited a range of approving responses from their health professionals leading to a meaningful engagement and outcome for both parties.

Confirmation / predictability

Many participants were frustrated and despairing with *nothing's working* frequently iterated, and no other more meaningful path offered.

Our research showed that the confidence to make change increases when you have greater certainty of what a treatment can and can't do for you, and therefore how far it can take you. Certainty requires confirmation on a treatment's capability. Without sufficient confirmation either way participants felt lost, that they were driving blind, unable to make sense of their options and choose the best way forward.

For some participants it was eye-opening coming to terms with the limitations of medicine. However, we found when participants were able to receive confirmation of how far a treatment could or couldn't help, it created an opportunity to review their options and empowered them to make change. They were able to let go of treatments that were no longer serving them and find others that could.

Alanna (11) is a case that typifies this, where none of the medical treatments were working for her and she was being persuaded to take higher and higher doses of pain medications as nothing else could be offered. Without the skills to determine the value of a treatment to her case,

or what could happen if she stopped the medications, she was afraid to change direction and as a result became stuck in a loop of failing health, increased medical costs and deteriorating quality of life.

Over the 12 month period, Alanna was able to take the reins of her own health and start moving forward. She was able to understand the triggers for her condition and her risks and from here make informed decisions on treatments based on what they could do and how far they could take her. She is now on minimum medication and her program is working for her.

I was able to let go of a lot of expensive adjunct treatments that weren't serving me. I am far more in the driver's seat feel like I am the expert in my own life rather than deferring to others. I have a team around me who listen and care about my ideas.

Positive feedback

Self-feedback

We saw how the small improvements generated through incremental change were enough to spur the participant forward. The positive feedback of the most worth was change that perpetuated the cycle of self-motivation particularly when the changes were sustained over a prolonged period.

I am self-motivated through the success I have had. I am now in a totally different place. I proved to myself that I could make change and do it – I felt empowered. I worked for this – I earned it!!! I feel so positive and proud of myself. (27)

Additionally we saw that when the benefits of change translate into an overall value that profoundly impacts one's life, then this type of feedback can transform the journey and set a new trajectory.

It's no longer important to me what others do. I realise that I am not responsible for others, although I will always help if we are on the same page. It doesn't stop me from putting myself first. (27)

I realise others may not be able to meet my needs. I am self-accepting of my own needs and I am no longer reliant on others to meet these. I am now able to be creative and I'm doing all sorts of things. (6)

The research showed that while support from family and peers may have been of great value, positive feedback or moral support from peers was *not* a requirement for change. This supports the fact that self-motivation, rather than motivation drawn from peer approval, is the key driver.

I am now proactive to change many aspects of my life and I don't feel the pressure of this type of need. It's no longer important to me what others do.

Professional feedback

We found that positive feedback from health professionals was a requirement for change. We found that the participant's doctor or medical specialist was the first point of reference when seeking clarification and confirmation to support change, and that being met with positive endorsement, rather than negative feedback was an impetus for change.

I liked the way we approach our doctors and ask them what they feel about our health and what they could do for us. I was able to get good clarifications of where things are. (10)

I'm not so afraid to seek help now as I would much rather be informed. I have seen all the specialists now and I am working with all of them. (5)

I have a team around me who listen and care about my ideas. (11)

I no longer have to ignore my health issues as I can talk to my GP and know what to ask. (15)

My relationship with him is better and he actually listens to me and he knows what I'm talking about and he trusts my judgment. (22)

I can communicate with my doctor so am able to go in the right direction regarding treatment. (27)

I feel like I've got control and not sitting there waiting for it happen. Everyone is sending reports to my GP and he is on the ball with where I'm at. (30)

Subject responses with objective measures

	Age	Sex	Health conditions	Key experience % change	Was the training worth it?	Key concerns	Key hurdles
1	67	F	Obesity, hypertension, NIDDM, osteoarthritis, sleep apnoea	Overwhelmed and fighting fires 9/10 to 6/10 (30%)	It has given me orientation of sorting out the smaller problems and working from there instead of the big picture which is too overwhelming – sometimes all I need to do is ask.	Financial impact of health	Procrastination Lack of willpower Unable to ask for support Lack of know-how
2	23	F	Rheumatoid arthritis; depression (undiagnosed)	Hopeless 5/10 - 2/10 (30%)	It's helped me to process my thoughts and feelings a lot better. I feel like I have more clarity and more direction. I feel like I can move forward in my life instead of being stuck in one place. I realise that my goals and future aren't affected by my condition so much so I don't worry about this.	Worried that health condition will limit job prospects. Fear of not being seen as worthy of contribution.	Affordability (no savings) Accessibility (no car) Know-how Self-doubt No direction or purpose Too comfortable where I am and it's stopping me from doing better
5	39	F	Obesity, diabetic, reproductive issues	Sad 9/10 - 2/10 (70%)	It helped me make good decisions. It made me discover that I had diabetes and gave me the confidence to get diagnosed. It gave me support and when I had a goal, I ran with it. I have done all the things that I put in place and I am happy. I now realise that I can be fixed.	Fear for future financial security Fear that health changes could destroy family dynamics and support. Fear for the future health for myself and my family.	Lack of family support Know-how Self-doubt
6	58	F	Extreme Stress, Depression, Anxiety, Osteopenia	Desperate 10/10 - 1/10 (90%)	It gave me the ability to assess clearly and process critically. It gave me clarity and confidence to break old habits and create something different to help me that is mentally and physically healthy.	No safe space in home Uncertainty/fear for future	Two dependents No space Uncertainty/fear for future

Motivation % change	Subjective feed back (motivation)	Confidence % change	Subjective feed back (confidence)	Proactive status	Health changes	Medication dependency
5/10 to 10/10 (50%)	I am adding more incremental change and making this a habit - so my momentum is continuing.	2/10 - 10/10 (80%)	I have tried new things and doing it differently; I am not as nervous as I used to be and this has rubbed off into how I handle medical people.	I have more control in some areas. I put in steps which are now a habit and can cope with the health of other people I need to help. It's important for me to be the strong one.	BP is even now not going up and down and can manage my blood sugar levels. I haven't had to take new or increase medications – I am still on track to reduce these. Have reduced thyroxine.	Reduced
5/10 to 9/10 (40%)	I am not caught up on the end goal anymore. I am more in the moment and focused on the immediate goals at hand which makes me feel it is more manageable which helps keep me motivated.	7/10 - 9/10 (20%)	I don't have to feel anxious about my condition anymore because I know how to get help and where to go for more information and just being informed has allowed me to feel more relaxed. I am no longer lost. I am able to deal with health questions really quickly & with ease.	It's kept me focused on being healthier rather than wasting time being stressed. I now live my life rather than dwelling on it. I put myself out there at work and took on responsibilities. It has opened up many opportunities. I now have savings and a car. I finished my traineeship and am looking for a job. I have direction. I go to the gym.	I feel a lot stronger, physically, mentally and emotionally. Keeping busy, less stress and I have more opportunities at work, which makes me feel like I can do anything. I don't think about my condition now and I don't think it limits me when I comes to work.	Maintained
3/10 to 8/10 (50%)	I am motivated to continue and try new things to help me and reach my target weight.	2/10 - 9/10 (70%)	I'm not so afraid to seek help now as I would much rather be informed. I have seen all the specialists now and I am working with all of them. I've just changed my diet.	I'm able to choose better options for my health now which impacts my family as well. It has meant that I have now learned that you can trust in the health system if you take time out to find out what's really wrong with your body and fix each one, step by step, till you get the result you're seeking. I'm heaps happier these days.	Lots of energy and enthusiastic. I can drive without worry of fainting. My breathing is fine and I can now sing. It doesn't matter to me that I haven't lost more weight. Was admitted to hospital with TIA	Increased Added medications for diabetes
6/10 to 10/10 (40%)	Bite sized pieces that the course has provided has enabled me to understand and put in place my strategy that has really worked for me. I now have an adult relationship with my nephew, my own space filled with magic and wind chimes.	3/10 - 10/10 (70%)	I can ask questions of professionals and not just accept.	I was able to get a care package for my mother and my nephew rehoused with treatment. I am now doing resistance training every week. I have created space/quiet time and I am meditating. I have peace.	I don't have emotional tiredness and my days are good now. My brain no longer churns at night and I sleep well, waking refreshed. I no longer cry a lot, nor am I withdrawn. I am now doing resistance training every week.	Reduced No longer taking any medications

Subject responses with objective measures, cont'd

	Age	Sex	Health conditions	Key experience % change	Was the training worth it?	Key concerns	Key hurdles
9	25	F	Environmental allergies Stress	Pressured 6/10 - 3/10 (30%)	Feel more relaxed and no longer look at things so seriously such as being judged by others. I am not a failure. If judgment comes I look at it differently and I can see that it may not be my fault if there is a problem.	Fear of being seen as a failure.	High self-expectations
10	69	M	Disc protrusion, CCL, Prostatitis, BPH	Conflicted 6/10 - 3/10 (30%)	More conscious of making sure that I'm putting parameters in so that I'm not over-committing. More conversations to ensure that we meet all needs means that I am at peace with my decisions and not meeting disapproval.	Fear of deterioration of back and ability to walk/maintain balance without checking before I move.	Over-committed Not prioritising exercise Conflict
11	25	F	Fibromyalgia, Joint Hypermobility Syndrome / Misc connective tissue disorder, Anxiety, Overweight, Anaemia, Bulimia	Hopeless and defective 8/10 - 2/10 (60%)	I looked at my health and life problems from a wider lens. I have been able to make incremental choices and changes by letting go of an 'all or none' mentality and instead focusing on what are the options available to me, and how they fit with my priorities. I have cultivated more of an identity outside of my illnesses and have financial and personal breathing room. I am less beholden to my illnesses to define me and the way my life is going to go.	Emotionally and physically trapped with a condition that was only going to get worse	Pain and exhaustion from condition Affordability Lack of support Difficulty in trusting others

Motivation % change	Subjective feed back (motivation)	Confidence % change	Subjective feed back (confidence)	Proactive status	Health changes	Medication dependency
4/10 to 8/10 (40%)	I am able to deal with uncertainty much better. Able to look at things more objectively.	5/10 to 8/10 (30%)	More confident in identifying my questions. I know how to gather information to make a wise decision.	I have changed my environment so there is less allergy from dust mite. I have worked at changing my perspective and at better communication. I am no longer stressed.	I have a new perspective and focus on my own circumstances rather than looking at others. I am no longer hard on myself. I no longer grab at things for fear of missing out. I understand myself and can deal with so much more. My allergies have reduced dramatically so I am no longer self-conscious.	Reduced
5/10 to 9/10 (40%)	Being able to discuss our needs has meant that I am not meeting disapproval and my motivation has now increased.	7/10 to 10/10 (30%)	I liked the way we approach our doctors and ask them what they feel about our health and what they could do for us. I was able to get good clarifications of where things are.	I don't take a day off as I know how important the exercises are and I don't let competing demands stop me. I have put a gymnasium in to make sure I can do these at home and ensure I keep the routine going	I am maintaining my health; I feel like a teenager, I am stronger physically than I have been for many years - even to stand still without shifting from leg to leg is a wonderful experience. Changed medication to better manage nocturia.	Maintained
4/10 - 9/10 (50%)	I was validated and learned that I don't need perfection or to be completely cured in order to progress. This helped me overcome a lot of psychological barriers and look for incremental change instead of one thing that would 'fix' me.	4/10 - 8/10 (40%)	I don't hand over my wellbeing to specialists any more. I was able to let go of a lot of expensive adjunct treatments that weren't serving me. I am far more in the driver's seat feel like I am the expert in my own life rather than deferring to others. I have a team around me who listen and care about my ideas.	I have much better capacity to manage my health and I can see that self-care is an investment not self-indulgence. I have gotten rid of that self-doubt voice. I don't compare myself to others. I feel like I know what works for me and a plant based diet has been surprisingly helpful in maintaining energy levels.	My symptoms have eased and I am not worried now. Everything I am doing seems to be working, but if I have a flare again I feel that I know who to go to to help me. This week for the first time in 3 years I haven't required any pain medication. I am finding some joy in movement now, I know the exercises that don't cause pain or injury.	Reduced

Subject responses with objective measures, cont'd

	Age	Sex	Health conditions	Key experience % change	Was the training worth it?	Key concerns	Key hurdles
14	51	F	Degeneration of L5/S1; Bulging disk L4/L5 with pinched nerve; Thyroid Nodules, overweight, menorrhagia	Lost and ugly 9/10 - 5-10 (40%)	It provided me with valuable information for me to take control of my own health. I now know the need for me to be the primary decision maker for my health choices. I have been able to make lifestyle changes that are sustainable and work for me. I am now confident that I can manage all aspects of my life, including health.	Anxious and stressed all the time with no positive outlook Fear of thyroid cancer Weight stops me engaging in social activities	Procrastination Doubt - nothing has ever worked, long-term Over-committed/ time poor
15	31	F	Graves Disease, POTS, obesity, anxiety	Hopeless 8/10 - 5/10 (30%)	You gave me the tools to talk to the doctors, you helped me sort out my goals - when they are written in front of me it is easier to achieve them. I could see how making one change would impact everything. I can deal with my symptoms better even though they haven't changed.	Anxious about being unemployable Feeling trapped and a failure Feels a burden on others Can't travel due to fear of fainting	Accessibility (no car) Health issues (feel sick most days) No motivation
16	55	F	Past history of breast cancer, currently anxious about recurrence; anxiety and stress	not completed	It gave me greater perspective and showed me what I should do which has meant that I could change direction from one which could have taken me further away from where I want to be. I am clearer in directions to get me to where I want to be.	Anxiety around cancer recurrence Lack of balance between home/work life	Over-committed Procrastination

Motivation % change	Subjective feed back (motivation)	Confidence % change	Subjective feed back (confidence)	Proactive status	Health changes	Medication dependency
2/10 - 9/10 (70%)	I just changed my lifestyle and am just doing it. I have reduced the time pressure by asking for and accepting help and I am good at saying No now.	3/10 - 9/10 (60%)	The education of how to review my symptoms and find links that provide knowledge that empower me to find the right health professional has been invaluable. The variety of therapies has enabled me to find the right program for me to reach my goals, which has meant that I have been able to drastically reduce the medications I am taking.	I have taken control of my health and well being in an informed way. I make choices that have benefited me greatly. I now prepare healthy and nutritious meals and have an exercise regime that feels right for me. Just doing it - but not in a fad way. My whole life has been doing things in a fad way - but I have made it a lifestyle way - so these consistent changes will remain with me.	The acute ailments that I had when commencing the program (i.e. lower back pain, ankle injury) are now not impacting my ability to exercise and function therefore have not impacted my life to the same extent. I was able to get into my bathers and go swimming in a public pool and also go for a run. I am no longer cranky with mood swings.	Reduced
3/10 - 8/10 (50%)	Implementing these different lifestyle changes helps to keep my mind and body healthier which has meant I feel better and saving money and taking driving lessons means I can afford a car and gotten my license which means more independence. I passed my exams and am ready to look for a job.	5/10 - 9/10 (40%)	I no longer have to ignore my health issues as I can talk to my GP and know what to ask. Before I was discouraged with treatment, overwhelmed and distrustful of Drs.	I am more proactive with making Dr appointments. I try to make healthier choices with my diet which makes me more confident about maintaining remission. Trying to eat healthier feel better and lose weight to keep my symptoms from flaring up. I did lose 5kg but I need to get a routine and stay motivated.	I am mentally in a much better place, but physically I haven't changed much. It was really good having someone to talk to. My heart palpitations have gone, and so has the pain in my legs, but my legs are not strong and it is hard to stand up sometimes.	Reduced No longer taking any medications
4/10 to 7/10 (30%)	Bad habits die hard. I have to make sure I stay on track. I enjoy my work too much and I procrastinate. But I have made some changes.	6/10 to 9/10 (30%)	More knowledge of what to do and how to do it	Exercise routine, diet routine	Lost 2.5kg Finger joints no longer swollen	Nil medications No medications at outset

Subject responses with objective measures, cont'd

	Age	Sex	Health conditions	Key experience % change	Was the training worth it?	Key concerns	Key hurdles
20	54	F	Pre-diabetic, Hypertension, obesity (60kg to lose), Arthritis, Bakers Cyst.	Overwhelmed 10/10 to 1/10 (90%)	It's given me the skills to handle everything on my own. It's helped me to be more confident in asking questions and not just relying on the doctor knows everything. It's given me a whole different outlook; I can deal with things instead of holding them in; I am more open and assertive which gives me confidence that I can be true to myself and not always giving in to people. I am happier and more relaxed. People have noticed. I've really grown through this course.	Concerned for future health security Being a burden on partner	Health issue (over-weight) Over-committed/ inability to say No
22	39	F	Lupus, Blood clots, High Cholesterol, Anaemia, Gastric reflux	Hopeless, overwhelmed 9/10 to 2/10 (70%)	A better understanding about my health issues and how to deal with health professionals in what I want and need. It has helped me manage my health issues in a better way and learn new strategies. Also learning about medications. I am no longer on Nexium – so less side-effects; learned the importance of stress and put plans in place and follow them to better manage.	Financial concerns - taking much time off work due to ill health without pay Cycle of stress impacts health/sleeping/energy	Over-committed (work load/work stress) Difficulty in accepting help Vicious stress cycle
26	57	M	Obese (55kg overweight), Type 2 diabetes, Hypertension	Powerless 8/10 to 4/10 (40%)	I always felt positive in that I could do this and achieve my goals. Being able to dig beneath the surface and unpacking some of the things I wasn't sure about has given me much more confidence and also solutions.	Concerned for future health security Cycle of stress impacts motivation	Lack of family support Health (low energy) Over-committed / not prioritising Difficulty in accepting help Doubt (insufficient discipline to do what it takes)

Motivation % change	Subjective feed back (motivation)	Confidence % change	Subjective feed back (confidence)	Proactive status	Health changes	Medication dependency
6/10 to 10/10 (40%)	Communication and planning is key. If I stick to things that are valuable to me I don't go off track. Accepting help has helped relationships grow and gives me more time to do things with my family. I've realised for my health I have to put myself first and I can then be there for others if they need it. I'll never go back.	4/10 to 10/10 (60%)	I can manage my journey and by writing things down it is on paper and there for me to read and then act on it. I feel I have the solutions. I have used the method with my GP and this has helped me get what I need from my GP. I am saving \$80 / month on medications I don't need to take.	I have kept with my program and only have 10kg more to lose. I see the dietitian and psychologist who help me stay on track. I am definitely on the right path and now looking at a home with a pool so I can do my exercise. I don't feel time poor because I prioritise and organise. Saying No has been a wonderful thing. I have saved enough money for myself and my husband to go on a holiday. This is money I said no to family and friends and put aside. It was a test to show me how much I was giving away so every time some asked me I would transfer that amount to another account.	Almost down to goal weight. I have no health issues now. I am enjoying life and doing things I have never done before going places and finding my inner peace. My sense of freedom is such that nothing creates anxiety for me to do physical things or go places. It is such a relief, and I can enjoy my life spontaneously.	Reduced No longer taking any medications
6/10 to 10/10 (40%)	Accepting help has been the most pivotal and it's freed me to do the things I want to do. I'm OK to not be perfect or win the mother of the year award. Peace and harmony through adding my family into my life and leaning on them when needed. I feel good, I can cope and put in place things for me.	3/10 to 10/10 (70%)	I feel more confident to question doctors and look for different answers. I can always get what I need and my GP is fab - he now asks me what I want. My relationship with him is better and he actually listens to me and he knows what I'm talking about and he trusts my judgment.	I am definitely not time poor. I shove stuff to the side and let things wait and am OK with this. I have changed my diet. I can maintain my B12 with diet and no longer need B12 shots. Also I no longer need to take iron due to better diet. I handle my emotional eating - I no longer do it on a grand scale.	My health is good and doesn't stop me anymore. I am infection-free and not needed to be hospitalised. I have seen a shift in my health and am worried less about blood clots. My cholesterol is down to normal so I don't need drugs.	Reduced
10/10 to 8/10 (-20%)	I lack discipline and have not achieved my weight loss. I am positive about what needs to be done. My motivation is helped by support from my family and colleagues. It would have been a lot harder without that support.	6/10 to 9/10 (30%)	Much better in that I'm not just willing to take what my doctor says. I can challenge and inquire about things more with him. <i>I haven't seen the GP. I am self-managing</i>	Choosing better food options & maintaining blood sugar levels. I have lost about 4kg from eating better. I am eating more plant based foods and no dairy. I am playing golf now and I walk more at work. I get 2000 steps in a day. I have increased energy and not lounging as much, but still haven't got an exercise routine.	I am maintaining blood sugar levels. My BP is OK. I needed to lose 55kg but have only lost 4kg.	Nil medications No medications at outset

Subject responses with objective measures, cont'd

	Age	Sex	Health conditions	Key sentiment % change	Was the training worth it?	Key concerns	Key hurdles
27	37	F	Migraines, endometrial polyp, cervical dysplasia, fibromyalgia, fibroids	Distressed and frustrated 9/10 to 2/10 (70%)	The logic that I learned from it works for me like a formula where I knew the answer and the light bulb went on. It changed my attitude in a very short time. I didn't expect to be able to change this behaviour so soon. Just being able to communicate with my doctor has been a very valuable lesson. I have learned how to cope and put in place a plan and have the motivation to follow through.	Disabling health Managing the burden of others Financial instability	Health issues (pain/energy/mobility) Over-committed Difficulty accepting help
30	46	F	Limited Systemic Scleroderma, Sjogren Syndrome, obesity (80kg to lose), heart problems, depression	Doom and gloom 9/10 to 5/10 (40%)	I've become more involved in what I need medically and better able to understand how to access different services and specialists and research medication. Helped me in my communication with specialists when discussing medications and my preferences. I did become more positive about my diagnosis but recently I have been told there is nothing more that can be done. Despite this I am pushing ahead and asking for what is right for me.	Disabling health/told there is no hope Financial costs of illness Fear of losing independence. The impact of my health means I can't do things, I had to change jobs because I couldn't get in and out of the car all the time.	Eligibility - no funding to help me Inability to ask for help Health issues Know-how/no-one will listen/what to do Accessibility (multiple specialists at different locations)

Motivation % change	Subjective feed back (motivation)	Confidence % change	Subjective feed back (confidence)	Proactive status	Health changes	Medication dependency
5/10 to 10/10 (50%)	I am self-motivated through the success I have had. I feel positive because what I am doing is working. I am no longer blaming my body. I proved to myself that I could make change and do it - I felt empowered. I worked for this - I earned it!!! I feel so positive and proud of myself.	6/10 to 10/10 (40%)	I know I'm on the right track. Because I have knowledge I won't just go and listen or do what they say because I know what I need now. It's been a really great journey. I can communicate with my doctor so am able to go in the right direction regarding treatment.	I have a job and money. Change in lifestyle was pivotal as was a root cause of my issues. Reducing my work hours and adding lunch breaks etc and walking has been a great healing thing for me. I am following a diet plan and also having TCM and herbs. This is really working for me. I also do the right exercise. I learned tossing away people's offer to help is a waste. I ask for help and my friendships have grown.	My mental health is vastly improved. My body muscle aches have gone - really brilliant gradual improvements. I did what I was told to do and didn't wait. And I kept on and it worked. I have very few migraines; I can walk and do more exercise without pain; I have no pain in my neck and shoulders; I have stable energy; my hormones are better so I am no longer worried about my fibroids.	Reduced Saved a \$4000 procedure and most likely more as I was not going the right way.
3/10 to 9/10 (60%)	It's hard to ask for medical help because it's gone backwards and they say there's nothing they can do for me. It feels like there's no point in asking for help. I feel roadblocked each time. I am still pushing ahead to be heard and determined to find someone to help. My family is very supportive - I have let go of not letting my mum and family members know what's going on	2/10 to 8/10 (60%)	I feel like I've got control and not sitting there waiting for it happen. Everyone is sending reports to my GP and he is on the ball with where I'm at.	My health did improve. I got a PT and changed my diet, but my health then deteriorated. I'm taking a lot more control. I no longer see the sleep or respiratory specialist at Prince Charles. It is all under the one hospital - the Gold Coast. I am pushing for surgery - if I have this I can reduce up to 15 tablets day. I have reduced my number of specialists. I do phone contact every 3 months and visit every 6 months with one specialist.	I did reduce the number of lung infections and did not need to be hospitalised for the whole of this last year. I have breathing problems, low iron/B12, terrible digestive issues, am 80kg overweight, have mouth ulcers, severe leg cramps and incontinence. If I can get the operation then I feel it's do-able, but if they say No then I feel then that's it, I'm done. There's nothing else I can do.	Maintained

Subject responses with objective measures, cont'd

	Age	Sex	Health conditions	Key experience % change	Was the training worth it?	Key concerns	Key hurdles
31	58	F	Type 2 Diabetes, High Cholesterol, Hypertension, 20kg Overweight, Anxiety, pain in digestion.	Helpless, depressed 10/10 to 2/10 (80%)	I realised how shit-ass the medical system is and how little they do for me. It made me realise that the help is worthless, and no one is going to help you unless you help yourself. Without the initial analysis of what caused the issues I wouldn't have got rid of my son. My health issues were secondary.	Concerned for future health security Extreme stress at home creating unsafe environment due to son's behaviour. Totally unmotivated <i>Life is in tatters. I have no hope, I don't care if I don't go on.</i>	Safety Lack of support Health issues (stress) Difficulty asking for help Self-critical

Motivation % change	Subjective feed back (motivation)	Confidence % change	Subjective feed back (confidence)	Proactive status	Health changes	Medication dependency
5/10 to 9/10 (40%)	Looking back my life is a total turnaround. Life isn't perfect but nothing is causing me issues. I asked my son to leave. Accepting that to go forward in a positive way, the lifestyle I had is not the appropriate one I needed to have, so I need to change this, and I have. I now make the best of it.	1/10 to 8/10 (70%)	I do believe I have the knowledge to make a positive change and I believe this journey has started. I truly am not going to live the rest of my life dictated by numbers - I am doing all the right things and if this doesn't work I don't give a shit. I'm doing my best.	I asked my son to leave and YFS helped. I now have stability. I am putting into practise the knowledge I had and I know I can do it now - I am eating better and from the garden! Although I still smoke I'm on top of this. I've come a long way in the last 9 months. I want to exercise and my lungs are freed up to be more active. It's a domino effect. Still going to gym, kept weight down and eating healthy.	I can move, I don't have joint pain, I think exercise has helped. My digestive issues have resolved. No more depression or anxiety I have energy and sleeping well.	Maintaining

I could see how the language participants used about their health began to change; often becoming more optimistic, and relating to their health conditions/treatment options using logical, problem solving language rather relying on emotions. they were able to speak about their health issues as problems that could be achievably fixed or managed, rather than spiralling after one discouraging health service interaction.

Savita Sandhu, Dietitian, Health Commons Advocate

Measuring the impact of health

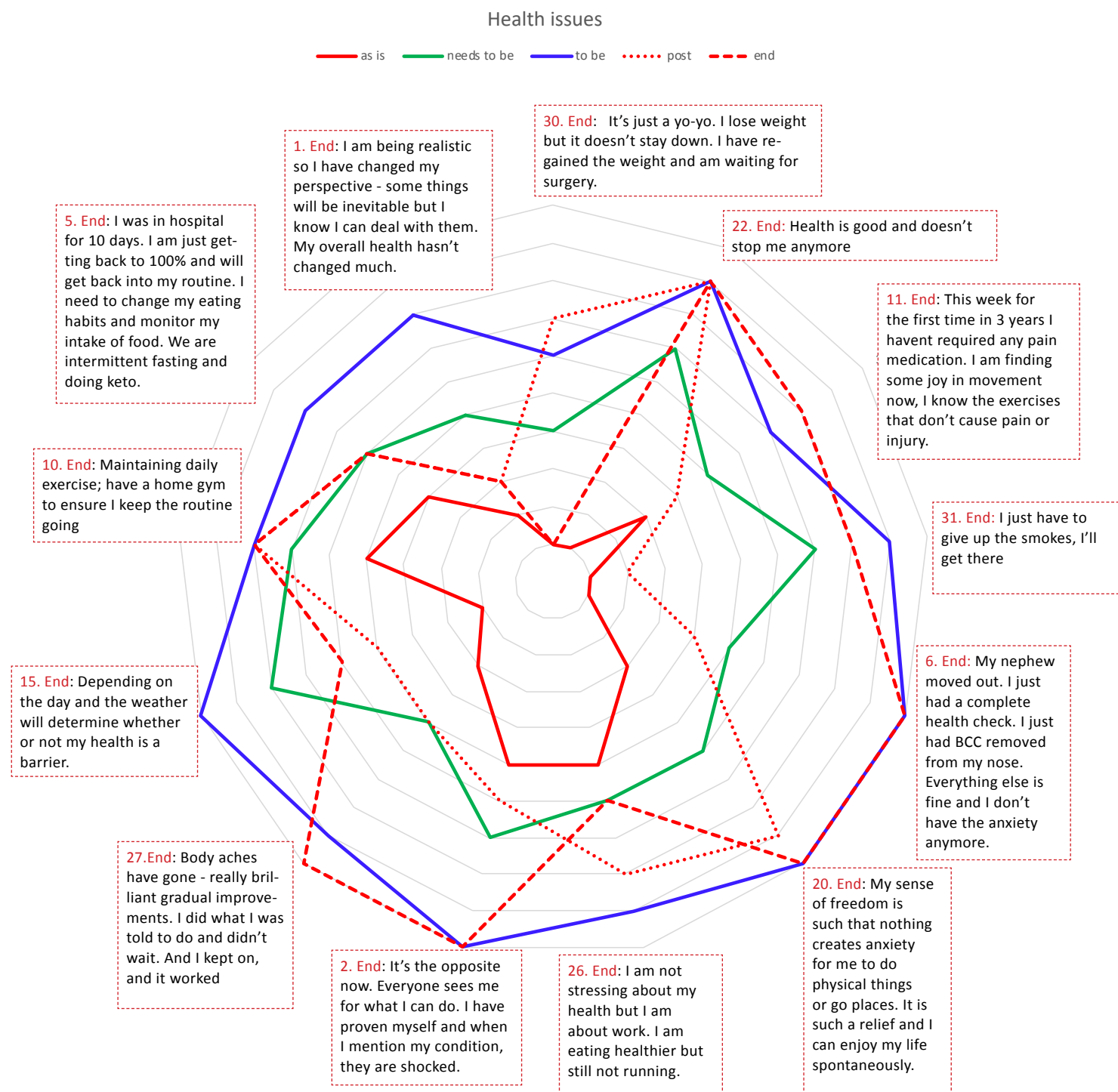
General Health Capacity: impact of general health on life



Comparison: impact of general health on life / impact of health issues as a barrier for the journey

	HEALTH CAPACITY (impact on getting on with life) AS IS, TO BE and 12 mo	HEALTH ISSUES (impact as a barrier for the journey) AS IS, TO BE and 12 mo
30	<p>My pain & shortness of breath makes it difficult to do things, limits my social life, time with my children, can't exercise and affects my sleep. My energy is very low and I feel depressed. I am embarrassed by the amount of medication I have to take.</p> <p>To join in and be social. To be pain and symptom free without medication and refreshed with the energy I need. This would make me happy with more self-confidence.</p> <p>I am more social. I have accepted that for now it's the way it's going to be. I know my limits and when tired I come home</p>	<p>I am just so tired. I want to exercise and eat properly in order to lose weight. I've tried many things and nothing is working. My pain restricts my physical exercise</p> <p>To be able to make it through a full day without being totally exhausted and scared I will fall asleep at my desk and scared that I won't be able to get up. No fear</p> <p>It's just a yo-yo. I lose weight but it doesn't stay down. I have regained the weight and am waiting for surgery.</p>
22	<p>My condition means it is hard to cope with work and family. I take a lot of time off work, now without pay. I may not be there enough for my children as much as they need. I am tired and when emotional, I want to overeat.</p> <p>Less stress and more energy to spend time with my kids and doing things for me. To feel strong and well to combat infection.</p> <p>More energy, not sick and in better place and have time to do things I want to do</p>	<p>Because I have anxiety and a lot of stress it means my emotional state is heightened. My family feel this as I become irritable and my health suffers ie sleep, eating, skin.</p> <p>I would have greater peace and harmony allowing me to have restful sleep and healthy eating habits.</p> <p>Health is good and doesn't stop me anymore</p>
11	<p>I am in pain from my joints and recurrent dislocations. I have disabling migraines and fatigue. My motivation and sense of optimism leaves me feeling hopeless. I can't work, and I am not the best partner one could be.</p> <p>To be in charge and knowledgeable about my condition with more ease of mobility.</p> <p>Different to what I thought. I have accepted that things may never be as easy as I want them to be, but I am aware of my limits and feeling stronger.</p>	<p>Because I get immobilised by pain I spend all my energy getting through the day and nothing left over for self-care.</p> <p>To be peaceful and have more holistic pain management</p> <p>This week for the first time in 3 years I haven't required any pain medication. I am finding some joy in movement now, I know the exercises that don't cause pain or injury.</p>
31	<p>I am not confident, I have a serious health issue and am totally unmotivated</p> <p>To feel good in my body and dress in what makes me feel good. To feel confident that my condition is under control.</p> <p>I get angry that I go back to smoking when I get stressed. Still going to gym, kept weight down and eating healthy.</p>	<p>Because I smoke and I am overweight it means that my diabetes is not in remission. I am stressed most of the time when my son is at home and I miss my ex-partner. So I basically think all the time 'why bother'.</p> <p>Having a support network that I can go to when I need to would bring me relief.</p> <p>I just have to give up the smokes, I'll get there</p>
6	<p>I get anxious and extremely stressed; I shut down and isolate myself. I have little joy and my heart feels dead. I have many responsibilities for others.</p> <p>To be able to relax in my own space would give me pleasure and happiness. I will be able to sleep without assistance.</p> <p>Still need assistance to fall asleep, but not through worry.</p>	<p>I am living with such family stress sometimes & I have to take calming medication before I go home. I sit in the drive or down the road because I don't want to go in.</p> <p>If my nephew moved out I would have the peace that I need.</p> <p>My nephew moved out. I just had a complete health check. I just had a skin scan and basal removed from my nose. Everything else is fine and I don't have the anxiety anymore.</p>
20	<p>I am embarrassed & self-conscious about my weight. It can't enjoy life and do things. My knees ache and I tire easily. I am concerned I am stopping my partner from doing things.</p> <p>Being able to enjoy life with eagerness, motivation and spontaneity. To run around with my grandson and do exciting activities, pain free.</p> <p>only 10kg to go; am now doing things away spontaneously, trying many things - no issues, life is really sweet</p>	<p>I find it difficult to do certain things and my anxiety sets in and my mind starts overworking to have a plan in place.</p> <p>Feeling comfortable in participating in whatever activities I am doing. It would make me feel like I have freedom.</p> <p>My sense of freedom is such that nothing creates anxiety for me to do physical things or go places. It is such a relief and I can enjoy my life spontaneously.</p>

Health Issues: impact of health as a barrier for the journey



Comparison: impact of general health on life / impact of health issues as a barrier for the journey

	HEALTH CAPACITY (impact on getting on with life) AS IS, TO BE and 12 mo	HEALTH ISSUES (impact as a barrier for the journey) AS IS, TO BE and 12 mo
26	<p>I worry about my future health and although I have lost weight I have lapsed into bad habits through comfort eating from stress and not exercising any more. It's hard to stay motivated.</p> <p>To be confident about managing my health and optimistic about my future.</p> <p>I'm still carrying a lot of stress and comfort eating, but I am eating better. I am only exercising once a week.</p>	<p>I have low energy which means it is difficult to discipline myself to do healthy lifestyle and exercise to get better.</p> <p>I still have work stress and it's a different kind of work stress with the trainees.</p> <p>I am not stressing about my health but I am about work. I am eating healthier but still not running.</p>
1	<p>I have poor mobility & balance due to knee/ankle pain which makes me lack confidence. I have poor energy & don't cope as well as I would like with daily chores. My weight impacts my life & I worry about diabetes as I have to monitor my blood sugar levels.</p> <p>Feeling confident and good about myself, having the mobility and the energy to walk and do activities, having the confidence to be in control of my health.</p> <p>Am coping better and have more energy and this makes me more positive that I can achieve what I'm setting out to do in small increments. I am no longer overwhelmed.</p>	<p>My health is gradually getting worse and impacting on many areas of my life as I age.</p> <p>With improving health I will be able to feel well and be confident about having an active future.</p> <p>I am being realistic so I have changed my perspective - some things will be inevitable but I know I can deal with them. My overall health hasn't changed much.</p>
2	<p>I never know when my condition's going to flare up. I don't feel like I have control over my condition and others see me as my condition. I feel worried about my future and discouraged about my future. I've lost motivation.</p> <p>To have direction and purpose in a job or role that I would love. This would make me feel free and independent.</p> <p>I am not as worried about my condition anymore and it has made me focus on other things.</p>	<p>My RA doesn't bother me much, it's more how people see me and what I can and can't do. I feel like I'm being judged unfairly which is frustrating. It impacts my confidence and motivation.</p> <p>Feeling free to do whatever I want to do; to be seen for who I am and not my condition. To be recognised for what I can do.</p> <p>It's the opposite now. Everyone sees me for what I can do. I have proven myself and when I mention my condition, they are shocked.</p>
27	<p>I am not a happy person and the quality of my life isn't good. I have intense migraines with vomiting and have to go to emergency sometimes for injection. I have an endometrial polyp and need surgery which is very frightening for me</p> <p>To have energy and less pain so I can live my full potential. To feel and look better, being both physically and emotionally balanced would bring joy and happiness to my life.</p> <p>My legs are improving - my aim was to run again and the treatments are helping me to improve.</p>	<p>I have body pain and migraines - but I still do all I can (work and study full time) and succeed - but the pain means I have little enjoyment. I am unhappy.</p> <p>With my body pain resolved I will be able to fulfil myself and enjoy the fruits of all my hard work.</p> <p>Body aches have gone - really brilliant gradual improvements. I did what I was told to do and didn't wait. And I kept on, and it worked</p>
15	<p>I am stuck and have no motivation to move forward. I don't like leaving the house. I have anxiety and no confidence.</p> <p>To feel motivated and in good spirits, looking good and going out with my friends. Having confidence knowing I have the right treatment and security having a job.</p> <p>I feel fine over all but I struggle with the heat. I feel fine leaving the house when it isn't hot. Now that I have my driving license and I have finished study I feel motivated but I still lack confidence and get anxious.</p>	<p>Being embarrassed and anxious about my symptoms and feeling sick most days. I have no motivation to move forward with life.</p> <p>To have a treatment plan that worked would make me feel motivated and confident that I was moving forward.</p> <p>Depending on the day and the weather will determine whether or not my health is a barrier.</p>

10	<p>Conscious of my back, I have to think about bracing myself, but it doesn't stop me from much. I am not too confident about my future.</p> <p>Peace of mind that what I am doing to maintain my health is the best possible I can do.</p> <p>I am maintaining my health; I feel like a teenager, I am stronger physically than I have been for many years - even to stand still without shifting from leg to leg is a wonderful experience.</p>	<p>I need to ensure I do exercise activities without letting competing responsibilities and activities stand in the way of regular exercise in order to maintain my movement</p> <p>By maintaining the strength I need to keep balance and minimise pain will ensure better mobility and balance</p> <p>Maintaining daily exercise; have a home gym to ensure I keep the routine going</p>
5	<p>I'm overweight, worried with churning brain; no energy and can't do much; I am useless and upset. don't sleep - my lungs get squashed</p> <p>To feel lighter and confident to do more physical activities. Knowledgeable to help my family.</p> <p>My dietitian said to eat less carbohydrates so I have just started the Keto diet to help with the heart, reduce blood sugar levels and reduce weight. Before Christmas I was in hospital for 10 days and had TIA - which are symptoms of a stroke which are caused by different lifestyle factors.</p>	<p>Unfit, not eating well, no routine, not constantly moving and gaining weight.</p> <p>A good role model for the boys having loads of energy to motivate others. Fitting into a size 14 again would be a dream.</p> <p>Over Christmas I haven't been very active and I was in hospital for 10 days. I am just getting back to 100% and will get back into my routine. I need to change my eating habits and monitor my intake of food. We are intermittent fasting and doing keto.</p>

“ It has meant that I have now learned that you can trust in the health system if you take time out to find out what's really wrong with your body and fix each one, step by step, till you get the result you're seeking. I'm heaps happier these days. ”

The Ready Reckoner Program

Can we bring this mainstream?

There is a pressing need for Health Commons within mainstream Australian health care. I believe health professionals do not currently have adequate resources to assist patients with unpacking and understanding their case in the way that Health Commons enables. This view has been consolidated by my clinical dietetic placement experiences.

Furthermore, as the burden of multimorbidity increases, we will need solutions that can be tailored to a variety of patients with unique combinations of disease. Health Commons has taught me that often just a few modifiable behaviours are responsible for most of an individual's health burdens, and by adopting a truly patient-centred approach to develop strategies to overcome these, multiple conditions can be managed simultaneously. While this approach works towards improving patients' quality of life, it also has the ability to reduce overall burden on the health care system through encouraging proactivity and selective engagement in services that are likely conducive to assisting patients, through a unique and personalised method. Additionally, issues such as health professional burnout, extensive waiting lists and financial burden on health care system and patients could be ameliorated.

Savita Sandhu, Dietetics graduate

The Ready Reckoner Program

At the outset we were scheduled to train participants who wanted to use the methodology to help others, either as a volunteer or in a professional setting. Due to COVID-19 we radically changed our plans and developed a more streamlined approach to enable advocates to facilitate a dialogue that was focused on the experience of a health consumer rather than on their medical diagnosis to enable that person to put in place a strategy that was contextual to their circumstances.

From the main learnings we noticed a strong aptitude for problem-solving, formulating solution-sets, and for re-search. We confirmed that with minimum guidance most people are capable of creating a strategy and choosing solutions that are within their capability, so long as the solutions are meaningful or contextual to their individual circumstances.

We developed an interactive Microsoft spreadsheet to collate the answers and produce outputs (radar maps, trees and alignment templates) that would give maximum comprehension to the user in return for minimum input. We unpacked the lifestyle root causes and used the person's narrative on the impact of those root causes as a back drop to finding solutions.

The data collected was used to populate surveys enabling participants to rapidly filter through their options, to determine the relative or potential value to their case of lifestyle change and treatments and make informed decisions.

We provided support in the form of short videos and the ability to download any required templates, and we structured simple questionnaires to enable people to seek qualification and confirmation around their treatment options.

This program provided me a very safe framework where I could facilitate clients in a holistic way that enabled us to work together to create a pathway forward that was meaningful to them. At no point did I feel out of my depth, even though I had no medical training. This is because the program focuses on the individuals experience of what their conditions mean to them, not on the diagnosis itself. Lizzie O'Keefe

I worked with two advocates as we tested and refined the model. Both were professionals, Lizzie O'Keefe a professional counsellor, who had supported me in running the training and research program, and Savita Sandhu, a dietetics graduate. The diagrams submitted are from one of Savi's clients. I encouraged both Savi and Lizzie to take clients on a six week journey, where they would meet with them once a week, generate the outputs and give them small amounts of homework.

The results and feedback indicate that there is potential to develop this product for mainstream, to be used as a self-learning, sense-making tool that empowers patients to make informed decisions, work with their health professionals and carve a strategy that supports their journey.

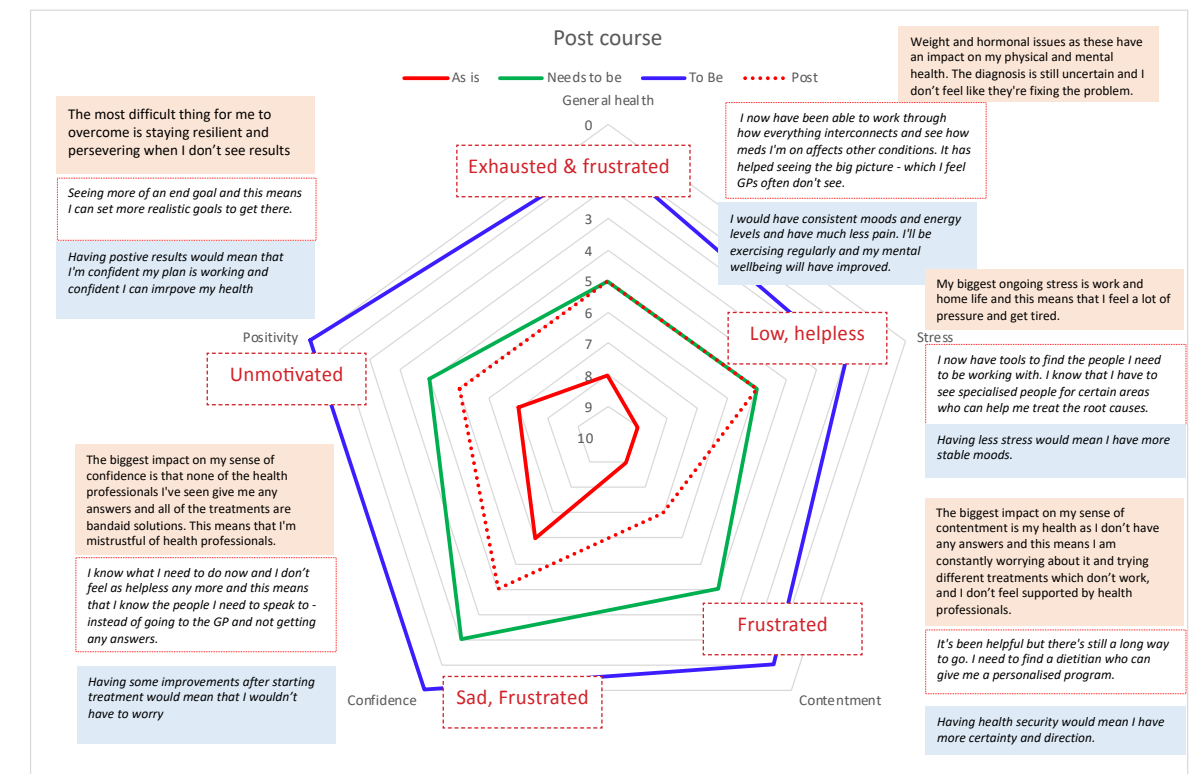
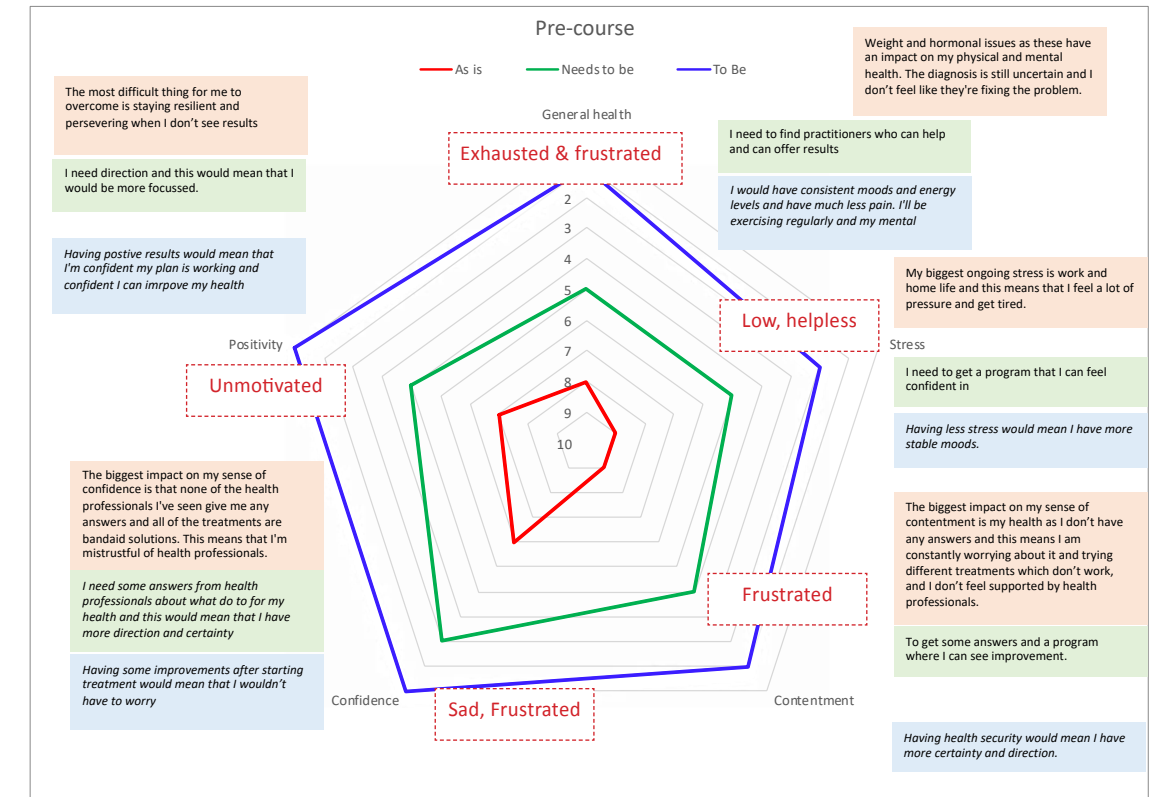
Feedback

Sentiment

We recorded progress at the end of the six weeks using radar maps (opposite). Savi, who took on five clients gave the following feedback:

All participants had a change in sentiment. When we started, almost all felt highly uncertain about their health and overwhelmed, almost like it was too difficult or complex to improve. At the end all participants seemed more assured and confident. Understanding their conditions and how their health behaviours contributed to these was one of the most empowering aspects, as participants could see exactly what they needed to do to improve. Some had no hesitation about making these changes – these were often the ones with more home support and perceived flexibility to change their environment (e.g. one person finished their degree and now chooses to work part time, another changed her work and home life schedule). Some participants struggled with this step. In two cases we identified

A health consumer's progress after the six sessions



resting more and reducing stress would be pivotal. Both cases found this extremely challenging, and often cited reasons, such as other family members being sick, insufficient finances to afford psychology, as to not doing this. From the perspective of the transtheoretical model, these participants fit the criteria of being in an earlier stage of change (contemplation). By the end of the program, both participants had progressed along the stages of change and begun small changes or were highly aware of the need to change (preparation and action stages).

Proactivity

Most participants that both advocates worked with became proactive, some more than others.

Lizzie had several who were very resistant to change and would not be a natural fit for this program. She noticed that those who were ready for self-betterment, that the program fast tracked their journey. She remarked at the strength and determination of these clients from where they were at the start to where they came to, and the transformation that occurred as a consequence.

I have seen a mixed bag of clients, some who were very resistant because they felt they had tried everything but nothing was working. The real changes required to make a difference seemed to be much harder for them than staying where they were. Whereas others I have seen have been so hungry to be in a better place than they were currently heading, were willing to take the bull by the horns and do whatever it took.

Savi: All participants I worked with were proactive with their health and conscious of the decisions they were making along their journey and the impact of these. About halfway through the Ready Reckoner program, usually after unpacking the causes and looking at personal health behaviours contributing to their situation, I noticed a marked increase in participants becoming more eager to research treatment options. They often presented me with findings or studies relevant to them without prompting, even before reaching the session where we would unpack this. They had also begun viewing these in a critical decision-making capacity, such as starting to weigh up pros and cons and consider the value to them specifically. These discussions were vital in the final sessions where radar maps are created to weigh up the value of treatments. Due to the structure of the Ready Reckoner program and the way it harnesses the participant's natural curiosity,

all people I worked with had begun to action their plan by the final session – whether this was getting a psychologist referral from their GP, talking to a specialist about changing medications or simply eating healthier. This is evident in the final scoring for some participants highlighting improvements in their quality of life and emotional wellbeing. All participants felt more empowered, which is a key determinant for positive health outcomes.

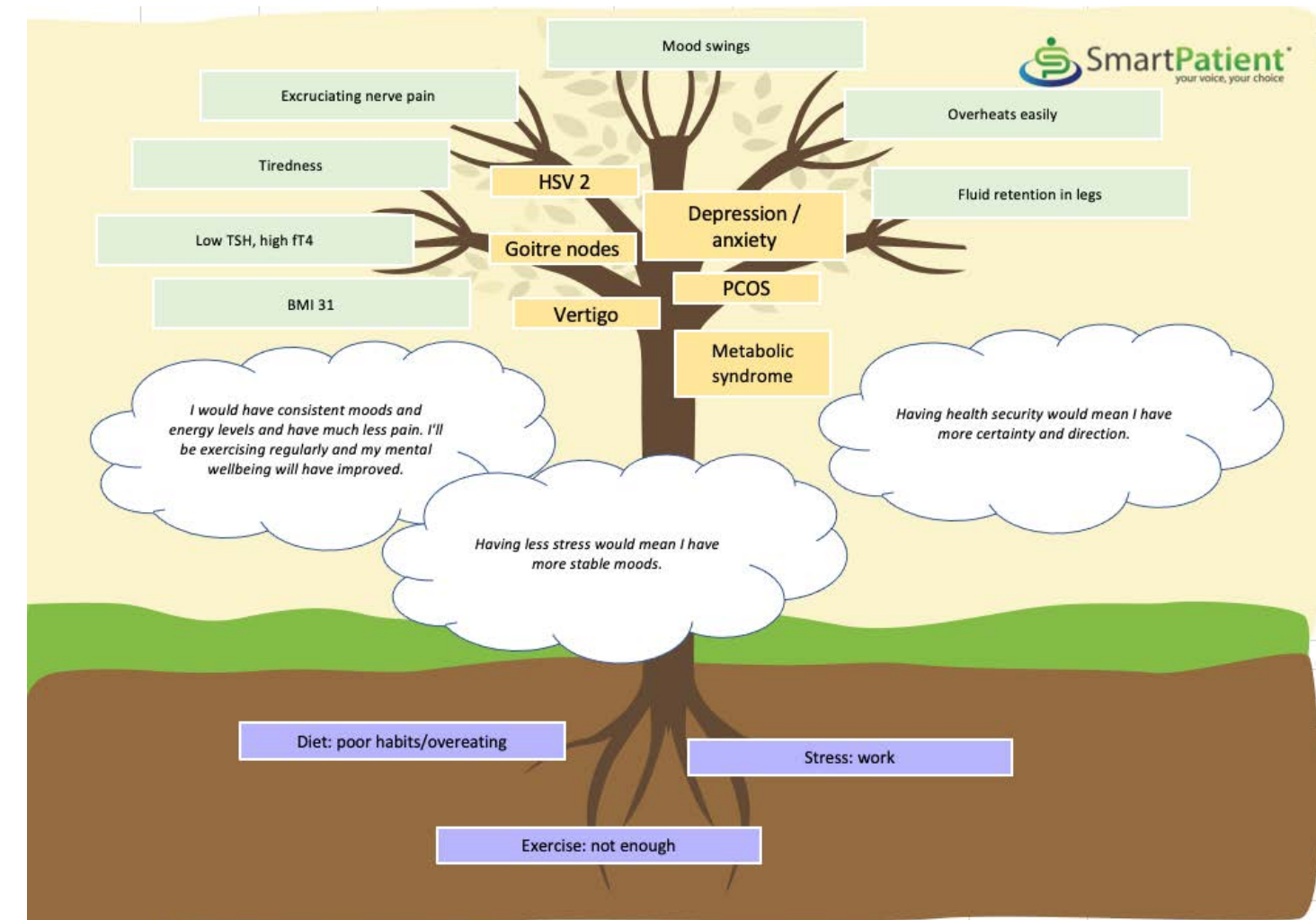
I did a 6 month check in with one participant. She fully actioned her plan as per the alignment template and advocated to find an endocrinologist who was in line with her endpoint. This shift, combined with a recognition that her own behaviours (overexercising, undereating, stress) could be at the root causes of her medical problems (no menstrual cycles, thought to be from a growth on the pituitary gland) caused her to seek dietetic support and reduce exercise. Within three months of this lifestyle change she had her first menstrual cycle at 21 years old, and her specialist adjusted her diagnosis from pituitary microadenoma to hypothalamic amenorrhea. The impact of this on her life was profound – she reported feeling much less internal turmoil and her stress about infertility had dissipated. She felt confident in her body, dating and being more social which brought a stronger sense of contentment.

However, some participants were more engaged and proactive than others. Participants with more support (family, partner, social, medical) appeared to be more proactive.

Two participants did not fully action their plan, however still managed to make improvements to their lifestyle through stress reduction and diet. As per the transtheoretical model, not everyone is in the same 'stage of change' and therefore results will always be different. However the unique benefit of the Ready Reckoner program is that I strongly believe that no matter where people are in their journey, or which stage of change they are in, Health Commons helps individuals progress along the model and thus become more proactive and empowered in all aspects of their life.

Confidence to make informed choices

Savi: Almost all participants reported printing out Ready Reckoner templates (usually the alignment template, health statement, conversational approach and/or radar maps) and either taking them to medical appointments as a reference or showing their practitioners to aid communi-



Measuring the value impact of solutions

MY THINGS OF VALUE							
Making our journey a possibility is all down to what we put into it, the changes we make and the support we get. Review those things that you felt would help and check the ones you did. If you did other things, then add these to the list and check which area/s they helped. Things of value range from things you did, people who helped, things you bought (gadgets/Apps), changes you made. Then score their value to you (high, medium, low) on making your journey a possibility.							
Make your list of what helped and score the value	Did I do this?	General health	Stress	Contentment	Confidence	Positivity	Value
Mindset work with a coach to build habits to help my health (e.g. meditation, strategy implementation)	Yes		X			X	Medium
Meditation - find guided meditations on youtube/spotify and schedule time for these	No						
Pre plan means using the meal planning template	No						
Cook myself dinner instead of just for the kids	Yes	X					High
Book in to see a dietitian with my EPC referral							
Shopping list							
Schedule walks	Yes	X	X			X	High
Start slow - 30 mins per day							
See an EP using my EPC referral							

cation. Through completing these templates, participants had a strong understanding of where they wanted their health to be (endpoint) and knew what to ask to find out if a practitioner could take them there.

One participant used the following approach when seeking a new endocrinologist. A key criterion for her was finding a specialist who would give her 6 months to monitor her hormone levels while she attempted to improve her condition through a lifestyle approach, before using hormone medications. She used the health statement template and conversational approach to ask qualifying questions before booking an initial appointment. This approach was successful – the participant found a specialist willing to try lifestyle treatments first, and did manage to resolve her condition through a purely lifestyle approach.

All participants reported that researching treatment options to understand their mechanism of action and potential for improving/hindering their life (SWOT analysis) was incredibly value, especially viewing these on radar maps.

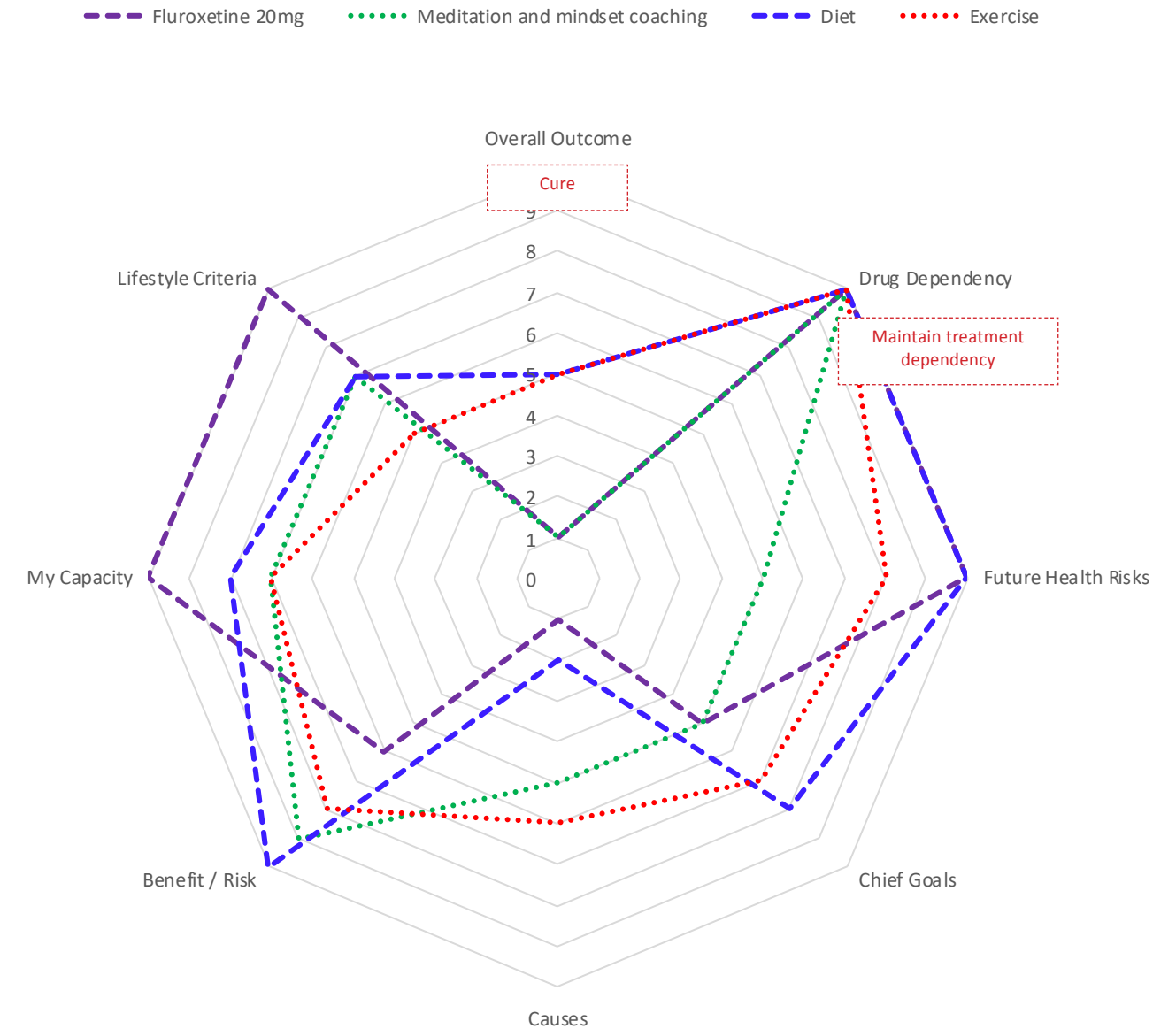
Another 19 yo F patient had endometriosis and wanted to weigh up her treatment options. She was considering the contraceptive pill, as her GP highly recommended this as a first line treatment. However, after researching the participant discovered that while the pill can improve certain symptoms, it can exacerbate the underlying medical problems. She highly valued her fertility and wanted to make

decisions now as a teenager which would support her later in adulthood. She chose to make dietary changes, reduce xenoestrogen exposure and exercise/stress manage first. In the final survey it is evident these behaviours already had begun having a great positive impact on her quality of life.

I believe a key driving factor behind increasing confidence was the participant-led research which opened up curiosity on their health conditions and treatment options using the structured templates. Once you understand the mechanics of a situation and how it comes about, the answers begin to reveal themselves. Through this method it is much easier for an individual to see which treatments are truly beneficial for them, rather than purely relying on the opinion of their health team or other people in their life.

When unpacking needs at the start of the program, it was evident that all participants felt overwhelmed with their health and were uncertain about how to progress. From working through the templates, I could see how the language participants used about their health began to change; often becoming more optimistic, and relating to their health conditions/treatment options using logical, problem solving language rather relying on emotions. they were able to speak about their health issues as problems that could be achievably fixed or managed, rather than spiralling after one discouraging health service interaction.

Depression: relative value of treatments



Some participants had everything stacked up against them, yet the human spirit is one of courage and self-determination and to be able to witness the growth and empowerment unfold in people is a true privilege. As an advocate, I am simply here on the side lines whilst they are doing all the hard work, and what the Health Commons program offers is a spring board that generates an appetite and belief that it is possible, no matter what one is facing, to take charge and create a life that is meaningful and fulfilling.

Lizzie O’Keefe

I strongly believe that no matter where people are in their journey, or which stage of change they are in, Health Commons helps individuals progress along the model and thus become more proactive and empowered in all aspects of their life.

Savita Sandu

APPENDIX 4

Where does crowd-sourced data fit within a hospital without walls?

Many health regions report that post-Covid budgets place a more significant strain on the financing of existing capital projects, such as hospitals. This problem creates new demands on administrators and clinical groups to develop innovative solutions that reduce risk, improve public value outcomes, and yet require no more new money.

Interestingly, in what would otherwise be considered a risk-averse culture with a strong reluctance to change, the willingness to change behaviour occurred during the height of the Covid surge impacting hospitals.

For example, in the USA, Microsoft demonstrated an unprecedented reduction in the time it took doctors to observe a range of beneficial clinical outcomes in several emergency departments and then implement the improved procedures across a group of hospitals in a health region. The willingness to collaborate, undertake problem-solving, sense-making and rapid implementation were underpinned by real-time data analytics that enabled continuous system improvement. The realized benefits included a dramatic 50% reduction of some invasive procedures and a reduction in deaths. The value impact on the system as a whole flattened the demand curve on intensive procedures within in ICU during a surge in demand.

As personal health monitoring devices and self-managing health Apps become more prevalent and the exchanging data between multiple parties outside of the conventional data footprint of a health region becomes commonplace, the opportunity exists for doctors and health administrators to include crowd-sourced data and analytics to significantly broaden its continuous improvement capacity. Based on the HCC grounded research, the indications are that the value impact upon the MSH region of crowd-sourced data could result in greater resilience, reduced demand on the health and welfare services and greater

The indications are that the value impact upon the MSH region of crowd-sourced data could result in greater resilience, reduced demand on the health and welfare services and greater productivity in the workforce.

productivity in the workforce. More research would be required to confirm the observations and validate the value impact potential where critical pain points within the MSH continuous system have been identified.

Health Commons Connect has demonstrated that health consumers can generate data that is far broader than the clinical, administrative and personal summary data generally associated with medical records. It includes information about health, welfare, resources, interactions, events, relationships, services, lifestyle, sentiment and many other aspects that impact their general resilience. The intention has been to translate the attributes of the program into a no or low-cost digital delivery program with human support within the region to develop the underlying capacity to leverage the value potential identified in the research.

It should be noted that people who invest time, effort and money to generate intellectual property about their own experience within the context of a health journey regard the data as their own, and there is a growing sentiment that health consumers intend to control it accordingly.

The next stage of the HCC program will enable this rich data to be captured and controlled by the individual and

by groups who wish to collaborate in order to address a given common interest. Legally informed consent is granted to HCC and any other parties they trust to act as custodian and data broker to use the analytics generated by the individuals, groups or the whole data for the common good. This included the notion of fusing grassroots crowd-sourced data with the regional MSH data that the research suggests would yield a unique hither-to unknown perspective revealing the relative value impact upon people, community and the region, of the beneficial services within the broader context of a person's condition and varying circumstances.

The research also hints at the possibility for MSH to capture these valuable digital data assets along the lines suggested by [Gartner](#) for the common good of all Queenslanders.

Provision will also be made in the HCC program that empowers individuals to grant conditional rights to monetize their tradable data assets via tokenization. This would include the notion of collaborating with public health systems in a manner that could help underpin the financing of our hospitals and regional services.

Potential value impact for business, government & local economy

The cost of absenteeism in Australia is estimated to be around \$3,270 per employee or 8% of the payroll for all organizations in the MSH footprint. This translates to a direct cost of \$578 per employee per day of absence.

Discussions with small, medium and substantial international organizations and some public sector organizations within the region also revealed an additional but much higher cost of low productivity due to presenteeism, which occurs when chronic diseases, such as mental illness, negatively impact productivity. An appetite exists to research the value impact of the HCC programme by these organizations and measure the value of their health-centric programs as part of the research.

The opportunity exists for HCC to demonstrate the relative value impact of the workforce adopting participatory health as well as sharing of responsibility and the adoption of available resources on absenteeism and presenteeism. Should additional research occur then it would be possible to evaluate the value and magnitude of generating digital assets with a market tradable value that could help offset healthcare costs.

A survey Virgin Pulse Global Challenge shows employees averaged four sick days a year but indicated that the time they lost while on the job (being present but not working productively) added up to a staggering 57.5 days per year per employee

Social Context

Leading economic commentators, including the World Bank, have identified a range of risks in a post-Covid economy that, if experienced in our region, could result in a higher level of exclusion for more people from more things they regard as essential, such as healthcare, due to increased consumer debt, lower incomes, fewer jobs, higher household bills and more 'zero hours' contract work.

According to the UK's leading healthcare reformist, Sir Muir Gray, the knowledge of 'what works' forms new digital assets, which will be worth more in commercial value than all the projected medical inventions over the next decade.

Social media and data storage platforms plus health consumers are already generating more data than our public health services have access to. This trend is likely to reach a tipping point where healthcare systems will require the ability to exchange data with patients and 3rd parties who own health data repositories. It is at this point that crowd-sourced data will become a highly valued commodity. The opportunity exists for MSH to establish itself as a trusted custodian of this data for the common good and individuals who rely upon its services in the short term via an extended HCC program. MSH could also acquire informed consent from these early health participatory consumer adopters to generate revenue and create digital assets that could offset the cost of implementing and operating a hospital without walls program.

Recommendations for the next stage of the journey

The ready reckoner

Development: convert the current excel ready reckoner tool into a fully functional App that anyone can use in a manner that validates the use of Low-Code development requiring very little time or cost from a technical developer using preformatted rules ensuring full compliance with MSH governance to enable the exchange of data.

Research: Test the adoption and use of the App in conjunction with community capacity building to validating compliance, adoption, value and any chosen outcome to determine the potential to generate sufficient crowd-sourced data to be of meaningful value to all the critical stakeholders. This would include the data requirements for MSH to better understand the patient/health consumer experience of what services and resources they use to get to where they need to be. This would be achieved by analyzing both this bottom-up data and the top-down system analytics

Community capacity building: Work with ADRA to develop an outline plan for staged community adoption of participatory health to build individual and collective capacity to better manage chronic disease and self-determined health journeys within the context of their circumstances. Assist ADRA to acquire support and any required funding to proceed with the plan and achieve the expected value impact outcomes for each named stakeholder in a given time frame

Data matching with core health systems data: Work with MSH to establish measuring criteria for crowd-sourced data that would enable the matching and fusion of data and any metrics with its health system criteria and analytical results

Topics to be discussed with MSH

Grassroots data classification & health system matching

- Governance & compliance
- Codify for Low Code App dev

Health Commons Connect App

- Stress test & compliance testing
- Trial in MHS footprint
- Launch to a broader market

Expanding data capture footprint beyond MSH

- Public health system support in other jurisdictions
- Financial opportunities for MSH

I no longer have to ignore my health issues as I can talk to my GP and know what to ask. Before I was discouraged with treatment, overwhelmed and distrustful of doctors.

A program participant