Developing a Frailty Coding Framework for the MYCaW® questionnaire

A project commissioned by NHS England and NHS Improvement South West Integrated Personalised Care team

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Meaningful Measures

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Helen is an experimental psychologist by training, and for the past 20 years has worked with voluntary, community and social enterprise organisations, supporting them to understand and communicate the impact of their work. Helen specifically understands the operating environment that many small organisations are facing, and the value that well-designed evaluations can bring to these organisations. As Head of Research and Evaluation at the integrative cancer charity Penny Brohn UK (2004-2019), Helen led a team of researchers who innovated a mixed-methods evaluation evidence base. This led to the publication of many academic papers evidencing the impact of the charity's work on patients. Since 2019, Helen has purely been a freelance research consultant working in collaboration with Dr Marie Polley on social prescribing projects.

1.0 Executive Summary

1.1 Introduction

As rates of frailty increase sharply in the oldest quartile of the population, and the average age of the UK population continues to increase, identifying and supporting people who are frail is an increasing priority for the NHS. Furthermore, the impact of Covid-19 has increased transition rates into frailty and increased the severity of frailty for many people.

The aim of this project was to investigate the feasibility of using the MYCaW® tool within a frailty service, to provide greater insight into the specific needs of people living with mild, moderate and severe frailty (as defined by the Rockwood Clinical Scale). MYCaW® is a very short tool, which can be routinely incorporated into a consultation to understand and prioritise what a person most wants support with. This can identify needs and concerns that may be different from the reason for the referral as defined by the practitioner making the referral. The tool enables the individual to assign a score to the problem/concern. A follow-up questionnaire enables changes in reported concerns and wellbeing over time to be measured. There is therefore the opportunity for both qualitative and quantitative data collection and analysis.

1.2 Method

Participants for this pilot were recruited either through their use of the Complex Care at Home Service (CC@H) provided by Gloucestershire Health and Care Foundation Trust, or the South Cotswolds Frailty Service (SCFS), which is an anticipatory care community service embedded in and delivered by the South Cotswolds Primary Care Network (PCN). All people within these services with a generated Rockwood Clinical Frailty Score, were eligible to participate. MYCaW® data was collected either face-to-face, over the phone, or via videocall. Data was also collected from healthcare practitioners about their experience of using MYCaW®. Data collection and storage was carried out in line with an approved NHS England (NHSE) Data Protection Impact Assessment.

1.3 Analysis

Patient defined MYCaW® concerns were organised into a bespoke qualitative framework of concerns and the frequency of concerns was analysed. This enabled an understanding of the range of concerns experienced by people living with frailty. A stratified dataset was created according to levels of mild, moderate and severe frailty, and concerns further analysed to understand how frailty impacts a person. Statistical analysis of concerns and wellbeing score changes identified whether people felt their concerns were being met and if their wellbeing had improved. Combined, these data allow service leads and commissioners to identify gaps in provision in meeting these needs and understand the breadth of concerns being supported by this service.

1.4 Results

310 people (257 from CC@H and 53 from SCFS) completed the baseline questionnaire and 113 people provided follow-up MYCaW® concern and wellbeing scores data. The modal person was 85-89 years old and female. Overall, the data shows a very positive picture of the services provided, with many patients appreciating the support and understanding showed to them. Despite experiencing moderate or severe frailty, patients' designated MYCaW® concerns scores showed statistically significant improvements, and a high percentage of people had meaningful levels of score changes. Similarly, there was a mean improvement in wellbeing scores that was statistically signifcant. When that data was stratified for Rockwood Clinical Frailty Score severity, only people experiencing mild frailty had a statistically significant improvement in their wellbeing. Rockwood scores did not change over time.

A bespoke MYCaW® frailty coding framework has been created through this project, by revising the existing coding framework for MYCaW®. This provides a rich picture of the breadth of concerns that are important to frailty patients. The most frequent concerns related to mobility, managing the household and activities of daily living (ADLs), physical problems, housing and independence. Importantly, this information can be used by healthcare practitioners to improve the personalised nature of the support they provide. (See separate document for the accompanying frailty coding framework.)

The MYCaW® tool was implemented in the services' systems and data was successfully collected from a fragile cohort during the Covid-19 pandemic. Staff experience of using MYCaW® showed that the measure was acceptable and worked well in practice. Implementation and guidance on how to use MYCaW® with people living with frailty was developed by the CC@H and SCFS teams in collaboration with Meaningful Measures Ltd. (See separate document for the accompanying detailed description of the implementation process within this pilot project.)

1.5 Limitations

This was a pilot project and therefore the n value is quite low. It is enough to demonstrate statistically significant trends in score changes and capture potentially 90% of all the concerns of patients living with frailty. The data should, however, be viewed as pilot data.

There were quite a lot of follow-up MYCaW scores that were not collected. It is anticipated that a proportion of patients died before follow-up or may have been admitted to hospital due to being more at risk of contracting Covid-19. This is reinforced by the modal age being 85-89 years old. However, hospital admissions and mortality data analysis was beyond the remit of this project.

The pressures of the Covid-19 pandemic and its impact on the frailty service may also have affected whether it was possible to collect outcome data.

1.6 Recommendations

To further enhance the current data, it is recommended that:

There is ongoing MYCaW® usage: Data on the experience of healthcare practitioners has shown that using MYCaW® was viable within consultation times, and was felt to be reporting useful data. It is therefore recommended that use of MYCaW® is continued within the frailty services and potentially implemented in other frailty services.

Understanding why follow-up scores were not always collected: Whilst 310 people filled in baseline MYCaW® forms, follow-up data was only available for 113. For quality improvement purposes, it is important to establish the reasons that contribute to this lower follow-up number, and this will determine if circumstances are beyond the control of the service or not. Admissions to secondary care, people passing away, or healthcare practitioners feeling unable to carry out a follow-up MYCaW® should be investigated as explanations.

Increasing volume of data collected: Once the reasons for not collecting follow-up scores are understood, more information will be known about why follow-up MYCaW® collection was low. It is ideal to have follow-up scores for 80% of service users to feel more confident that the mean data represents the majority of services users. It is also recommended that a minimum of 120 patients with baseline and follow up MYCaW® scores are analysed for each service provider to enable enough power to be confident in the statistical analysis and the overall trends that are emerging.

Further understanding how severity of frailty affects wellbeing: It is recommended that enough MYCaW® data is collected at follow-up to have at least 120 patients in each frailty group – mild, moderate and severe. This will enable confidence in the statistical analysis and will highlight how the degree of improvement in MYCaW® scores and wellbeing may be affected as frailty become more severe.

Further understanding how the patterns of MYCaW® concerns change with the severity of frailty: We reported a noticeable change in the frequency of MYCaW® concerns when the dataset was stratified according to the Rockwood Clincal Scale. It is recommended that this frequency analysis be repeated when there are at least 200 patients with MYCaW® concerns in each of the mild, moderate and severe categories according to the Rockwood Clinical Scale. This will provide useful information to help services predict the type of concerns they are most likely to encounter depending on the severity of the frailty.

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2.0 Introduction

Frailty can be described as a group of issues which are associated with a decline in physiology, psychology and cognition in a person[1,2]. As the level of frailty increases, people become more vulnerable to stress, mainly manifested by a reduced physiologic reserve in metabolic, immune, and neuromuscular systems. The impact of frailty can be quite diverse. For instance, it can lead to a loss of resilience in situations which may normally be overcome, for example a minor health complaint like an infection may lead to long-term complications and problems, severely impacting health and wellbeing. A reduction in physical activity can lead to a decline in the musculoskeletal system therefore increasing risks of falls. The increased risks of falls, disability, institutionalisation and mortality[3,4,5] have been well documented in the research literature.

More broadly, frailty is described as: *"a person's mental and physical resilience, or their ability to bounce back and recover from events like illness and injury."*[6] . According to Age UK, approximately 10% of people aged over 65 live with frailty. The proportion of people with living with frailty increases sharply in the population aged 85 and over. Here between a quarter and a half of this population are affected[1]. As the rates of frailty increase sharply in the oldest quartile of the population, and the average age of the UK population continues to increase, identifying and supporting people who are frail is an increasing priority for the NHS. As such changes to the NHS GP contract in 2017/18 saw the introduction of routine frailty identification for people 65 years and over, with the aim of providing early support to help people continue to live independently for as long as possible.

2.1 How is Frailty identified? The Rockwood Clinical Frailty Score

There are several measures and approaches to assess the level of frailty that a person is experiencing. For this project, the Rockwood Clinical Frailty Score[7] (see appendix C) was used, as it had already been implemented in clinical practice. This tool is a widely used, holistic clinical measure of a person's level of vulnerability, or frailty. It is generally carried out as part of a holistic assessment for people over the age of 65 years. The NHSE publication 'Community services currency guidance: frailty and last year of life'[8] states that mild, moderate and severe frailty on Rockwood are classified as follows:

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[1] NHS England: Toolkit for general practice in supporting older people living with frailty https://www.england.nhs.uk/publication/toolkit-for-general-practice-in-supporting-older-people-living-with-frailty/

[2] Clegg A et al (2013) Frailty in elderly people. Lancet 381 (9868): 752-762.

[3] Kojima G (2015) Frailty as a predictor of future falls among community-dwelling older people: A systematic review and meta-analysis. J Am Med Dir Assoc 16(12): 1027-33.

[4] Cunha A et al (2019) Frailty as a predictor of adverse outcomes in hospitalised older adults: A systematic review and meta-analysis. Journal of Epidemiology 27(8): 347-353.

[5] Muscedere J et al (2017) The impact of frailty on intensive care unit outcomes: as systematic review and meta-analysis. Ageing Res Rev 2019; 56: 100960.

[6] https://www.ageuk.org.uk/our-impact/policy-research/frailty-in-older-people/understanding-frailty/

[7] Rockwood K et al (2005) A global clinical measure of fitness and frailty in elderly people. CMAJ 173: 49-495.

[8] https://www.england.nhs.uk/wp-content/uploads/2021/03/21-22NT_Community-Frailty-and-Last-Year-of-Life.pdf

- "**Mildly frail (CFS score of 5 or less)** These people often have more evident slowing and need help in high order IADLS (instrumental activities of daily living e.g., finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.
- **Moderately frail (CFS score of 6)** People need help with all outside activities and with keeping house. Inside, they often have problems with stairs, need help bathing and might need minimal assistance (cuing, standby) with dressing.
- **Severely frail (CFS score of 7 or more)** Completely dependent for personal care, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying within 6 months."

A more detailed interpretation of the Rockwood Clinical Frailty scores can be viewed here[9].

2.2 How has the Covid-19 pandemic impacted upon frailty?

Research is now emerging which is reporting on how the Covid-19 pandemic has impacted upon people living with frailty. The drastic change to people's lifestyles here in the UK and around the world due to the Covid-19 pandemic are thought to be the cause of the increase in *"corona-frailty"*. There is still a lot more to be understood from ongoing research studies as the longer-term impact of successive lockdowns continues to emerge, however this section will briefly highlight key findings that have been reported.

There were more severe impacts upon the frail population from Covid-19, as they were statistically significantly more likely to need admission to ICU, be mechanically ventilated or die, if they were infected with Covid-19[10,11]. This was expected due to the known increase in mortality in frail patients generally but has now been confirmed in at least 17 studies.

There was a reduction in physical activity in older people during the pandemic and the enforced lockdowns. For some people who are less frail, they could become more physically active once lockdowns were lifted. However, many became habitualised to less physical activity. A comparison was carried out of the effect between frail populations in Spain, where no physical activity was allowed during lockdown, and in the UK where physical activity was allowed during lockdown[12]. This showed that the frail populations in both countries had an increase in frailty during lockdown, particularly the first

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[9] https://www.bgs.org.uk/sites/default/files/content/attachment/2018-07-05/rockwood_cfs.pdf

[10] Hewitt J et al (2020) The effect of frailty on survival in patients with COVID-19 (COPE). The Lancet Public Health, 5(8): 3444-3451.

[11] Yang Y et al (2021) The impact of frailty on COVID-19 outcomes: A systematic review and meta-analysis of 16 cohort studies. J Nutr Health Aging, 25(5): 702-709.

[12] Garner et al (2021) An observational cohort study of longitudinal impacts on frailty and well-being of COVID-19 lockdowns in older adults in England and Spain. Health Soc Care Community Jan 28. doi: 10.1111/hsc.13735.

lockdown, but it was more severe in the Spanish population. The authors highlight the lack of physical activity as a key reason for the differences between the Spanish and English populations.

Further research in Japan specifically identified the relationship between the transition to becoming socially frail and the imposed lockdowns, due to the lack of social interaction and increased isolation at home[13]. These researchers further identified an increase in depressive symptoms in older adults, also thought to be caused by having to stay at home. There is currently little other research that specifically examines if frail people were more impacted by loneliness and isolation compared to the general older population.

2.3 How were Gloucestershire CCG frailty services impacted by the Covid-19 pandemic?

In many cases, healthcare practitioners supporting community-dwelling frail people during the pandemic have noticed many effects, and some that are not yet being reported in the literature. There were complex and interlinked consequences in the way people could access the NHS during the pandemic. The observations below from both organisations taking part in this pilot project give a clear picture of how service provision changed.

The CC@H team supported the wider Covid-19 response, particularly with reference to hospital discharges and emergency department (ED) referrals. All ED and acute hospital referrals were seen within two working days and were less likely to spend 12 weeks in the service. Many required a more medical model approach to their care and treatment plan as they tended to be more acutely unwell. In addition, the people referred from other non-acute hospital teams were more deconditioned, less mobile and more anxious than people previously referred to the service. GPs were not routinely seeing people with mild frailty in primary care, unless they were unwell, and therefore not referring them to the service. Proactive, preventative support was therefore not available to many older frail adults during this time, which is and may continue for many years to be an indirect adverse effect of the Covid-19 pandemic.

The Covid-19 pandemic impacted the delivery of the South Cotswolds Frailty Service (SCFS) in a number of ways, many of them similar to the CC@H service. People's worlds shrank, often to the size of their living room, and being unable to maintain their muscle strength in their smaller world meant a significant decrease in mobility and a decrease in the motivation and capacity to keep active.

Services were both redeployed and most were not visiting people in their own homes. The impact on physiotherapy and occupational therapy services meant that SCFS was unable to refer people in need of specialist assessment, treatment and equipment. GP services were, for the most part, not visiting people in their own homes, and they often relied on SCFS Community Matrons to be their eyes and ears in delivering medical care.

People with frailty often experienced significant isolation prior to the pandemic, but the impact on people's usual avenues of support was significant. People's informal support from family, friends and neighbours vanished overnight, and for many it never returned. Formal care was stopped for many, leaving people with unmet needs to try and fend for themselves. SCFS team members continued to see people during the pandemic and were often the only human contact people had. There was little/no capacity for mental health services to provide support for low mood and anxiety.

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[13] Kodama A et al (2022) Impact of COVID-19 pandemic exacerbation of depressive symptoms for social frailty from the ORANGE registry. Int J Environ Res Public Health 16; 19(2): 986.

The multifaceted impact of Covid-19 and lockdowns highlighted above has demonstrated an urgent need to understand how people living with frailty now need support, to enable the care to be efficient, joined up and as supportive as possible. The Personalised Care team at NHS England & Improvement Southwest, recognised a need to be more personalised in how they managed, prioritised and documented people's unmet needs in the frailty services, especially as the pandemic had shifted usual practice. The following section details the approach that was piloted.

2.4 How can concerns of people who are frail be identified? Potential use of the MYCaW® scale

The Measure Yourself Concerns and Wellbeing (MYCaW®) questionnaire is a validated Patient Centred Outcome Measure, trademarked and licensed by Meaningful Measures Ltd[14] (see appendix A). Initially developed for use in holistic cancer support settings, it has also been used with carers, in social prescribing, and to improve workplace wellbeing across a number of different cohorts and in a range of countries including the UK.

MYCaW® is a very short tool that can be routinely incorporated into a consultation to understand and prioritise what a person most wants support with. These needs and concerns may be different from the reason for the referral as defined by the practitioner making the referral. The tool enables the individual to assign a score to the problem/concern. A follow-

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[14] https://www.meaningfulmeasures.co.uk/

up questionnaire enables changes in reported concerns and wellbeing to be measured over time. There is therefore the opportunity for both qualitative and quantitative data collection and analysis.

A framework of the amalgamated concerns reported by individuals sits alongside the questionnaire. This aids service leads and commissioners in developing service models to best fit the needs of individuals, through understanding the concerns most frequently reported and enabling statistical analysis.

MYCaW® is not routinely used in services for people living with frailty, however the questionnaire is already used in social prescribing schemes where a proportion of patients are frail. MYCaW® therefore has the potential to be a useful person-centred outcome measure within this area, helping people at many different levels within the NHS to understand better 'what matters' to the person with frailty.

2.5 Descriptions of the two services that are providing MYCaW® and Rockwood data for this report

The Complex Care at Home Service (CC@H) provided by Gloucestershire Health and Care Foundation Trust is an anticipatory care community service operating in Cheltenham, Gloucester, and Forest of Dean Integrated Locality Partnership geographical areas. The service focuses on identifying people who are losing resilience and independence, increasing in frailty and at risk of hospital admission or long-term care. The team is multi-disciplinary, led by Community Matrons and includes dementia specialists, therapists, Health and Wellbeing Coordinators (H&WBC), a dietitian and social care practitioners. CC@H is a preventative model employing a case management approach. This encompasses the proactive identification of people losing resilience, independence, and ability to self-manage, and the adoption of a strengths-based, coaching approach to person-led goal setting. The team works closely with the person and resources in the community to identify and access longer-term low-level support to maintain benefits. The service is not intended to be an urgent care service. The service offers three levels of intervention:

- Pathway 1 - Telephone Support Service in partnership with primary care. Risk stratification of GP Practice lists identifies a cohort of people who are likely to benefit from a wellbeing telephone call. The individual is offered a welfare check, onward referrals and is stepped up to Pathways 2 and 3 as required.
- Pathway 2 - Proactive Wellbeing/Prevention led by H&WBC. Once referred to the Wellbeing Prevention arm of the service, the person will be placed on the H&WBC caseload. H&WBC will be expected to ensure the person receives an initial telephone call within five working days to undertake an initial telephone assessment. A questionnaire is completed during the first telephone assessment. If high level clinical needs are identified, H&WBC escalate the person to a community matron, community dementia matron, occupational therapist and physiotherapist as appropriate.
- Pathway 3 - Clinical Case Management. The day-to-day clinical work is led by the Community Matron. At the time of admission, the Community Matron will visit the person at home and conduct a full holistic assessment (Comprehensive Geriatric Assessment) within 10 working days. This record, and all further entries by the service staff, will be entered into a single record, and additionally recorded at the patient's GP practice. The team will spend time, over several weeks (10-12 weeks maximum time in service), building a therapeutic relationship with the person, their main carer or family member, to ensure that the best possible health and wellbeing goals set by the person can be realised.

The service is working with other partners in the system to provide co-diagnosis of people with dementia to ensure diagnosis is timely.

South Cotswolds Frailty Service is an anticipatory care community service embedded in and delivered by the South Cotswolds PCN. The service focuses on identifying people who are losing resilience and independence, increasing in frailty and at risk of hospital admission or long-term care. The team work with people with a Rockwood score of 6 and above; promoting self-management of health conditions and maximising independence, through to supporting those with severe frailty in their last phase of life. The team is comprised of Community Matrons and Wellbeing Coordinators. They work directly from the GP patient lists, where people are risk stratified according to their level of frailty. They provide wellbeing interventions, accessing low-level community support as well as complex case management for those triaged as requiring this intervention. The day-to-day clinical work is led by the Community Matron. At the time of admission, the Community Matron will visit the person at home and conduct a full holistic assessment (Comprehensive Geriatric Assessment). This record, and all further entries by the service staff, will be entered into a single record at the patient's GP practice. The service is working with other partners in the system to provide co-diagnosis of people with dementia to ensure diagnosis is timely.

2.6 Aim of this project

The aim of this project was to investigate the feasibility of using MYCaW® within a frailty service and developing a bespoke qualitative framework of concerns, to provide greater insight into the specific needs of people living with mild, moderate and severe frailty (as defined by the Rockwood Clinical Scale). The resulting frailty concerns framework and statistical analysis will enable: understanding of the range of concerns experienced by people living with varying degrees of frailty or complex conditions across a number of settings; measure the change in wellbeing of individuals through involvement with these services; and to identify gaps in provision in meeting these needs for the attention of service leads and commissioners.

3.0 Methods

3.1 Development of the implementation of MYCaW®

Implementation and guidance on how to use MYCaW® with people living with frailty was developed by the CC@H and SCFS teams in collaboration with Meaningful Measures Ltd. A separate document with a detailed description of the implementation process within this pilot project accompanies this report. The implementation is briefly summarised below, and staff experiences recorded.

3.1.1 Development of data collection process

The clinical teams, management, and members of Meaningful Measures coproduced the implementation process during monthly meetings, with a particular focus on high quality data collection and reporting. Two training sessions on the administration of MYCaW® for patient facing staff were provided by Meaningful Measures. Meaningful Measures addressed any issues with collecting data from a frail population and produced a set of guidance notes. These guidance notes covered scenarios where it was not appropriate to collect data and how to ensure data was collected which captured the patient's voice. Guidance was also given for instances where it is appropriate for members of staff to capture the concerns of patients who may not be able to determine these themselves (due to extreme frailty or dementia).

3.1.2 Development of digital data capture processes

During the project work and meetings, Business Intelligence (BI) staff within the CC@H and SCFS teams, in partnership with Meaningful Measures, were also able to develop their digital systems to capture the MYCaW® data and produce reports. A template was created for EMIS and SystmOne using temporary codes for the MYCaW® questions, which allowed data capture from the first MYCaW® to be piped through at the point of follow-up. Reporting to create an excel file of data for analysis by Meaningful Measures from the EMIS and SystmOne templates were then developed.

3.1.3 Development of data security processes

MYCaW® data was cleaned by the BI team to remove any identifiers (names/ locations). Care was taken to ensure data transmission was done in a secure way (via password protected Excel file sent to a secure NHS England & Improvement email address held by Meaningful Measures). Meaningful Measures also ensured compliance with the DSPT (Data Security Protection Toolkit) to enable appropriate processes in terms of digital security, storage and management of data.

3.2 Participants and recruitment

Participants were recruited into this project by their use of the CC@H and SCFS services. All people within these services with a generated Rockwood Clinical Frailty Score were eligible to participate with the following inclusion criteria:

Inclusion criteria

- Adults living in the community and living with frailty who were under the care of frailty services across a variety of settings – specifically CC@H, the SCFS, Frailty Nurses/Matron in primary care (people who were eligible for a Rockwood scale assessment).
- Services working with adults with frailty in the community, ideally working in a personalised way e.g., using health coaching and personalised care and support planning.

Exclusion criteria

- People living in care homes
- People under the age of 18
- Anyone not classed as at least mildly frail on the Rockwood scale

Participation was optional and text at the top of the questionnaire was shown and/or read to all people who were eligible to provide their data for this project. People were given the chance to opt out of the project at this point and not provide their data. See Appendix A for the full text which mentioned that unidentifiable, GDPR compliant, anonymised data (age band, gender, ethnicity and first three letters of postcode) would be shared with Meaningful Measures.

3.3 Data collection

Rockwood data was collected during the initial assessment point when accessing the frailty service and the resultant score was used to determine the severity of frailty experienced by the patients.

3.3.1 Data collection process by CC@H provided by Gloucestershire Health and Care Foundation Trust

Baseline data collection:

After consent was given, MYCaW® data was collected by Community Matrons or link workers, who presented the consent sheet and MYCaW® tool to people on paper during the first consultation session. MYCaW® asks every person to identify the concerns that are most bothering them and then rate the severity of these concerns and their level of wellbeing. Where possible, patients completed their own forms, however, sometimes the member of staff / practitioners scribed the responses verbatim (this was paramount as the voice of the individual is required for MYCaW® data). There was also opportunity for proxy informal carers to fill in the questionnaire on behalf of the patient if this was needed, again they were asked to write the responses verbatim. The person completing MYCaW® was designated on the first page.

Data was collected either face-to-face, over the phone, or via videocall. Face-to-face data was collected on paper forms, which patients could either write on or others could scribe for them. When over the phone/videocall, the MYCaW® tool was read out via a script (see accompanying implementation document for script), which ensured consistency of data collection with MYCaW's® 0-6 scale presentation. When data was captured over the phone/video call, responses were recorded in SystmOne. When the data was captured face-to-face, the written responses were photographed on the member of staff's work phone and then emailed to an administrator who input the data into the patient's digital record (SystmOne). The photograph was then deleted (see accompanying implementation document for the procedure).

Follow-up data collection:

Follow-up data was collected either face-to-face, or via phone/videocall as in the first data collection time point. Original MYCaW® concerns written down at the first time point were found on the SystmOne notes and read out or shown to the patient on a digital display. The patient then had to provide their answer on the Likert scale of how the concerns and wellbeing were scored at follow-up. Two free-text questions were then asked, and the practitioner captured the responses from the patient or proxy caregiver verbatim on the digital system.

Additional qualitative data collected from staff about their experience of implementing and using MYCaW®:

Perspectives from members of the staff team using the MYCaW® tool to gather data and record it digitally within the system were also captured. Five questions were sent out in September 2021 (via email) to all staff working on the implementation of this project within the CC@H and SCFS teams. These questions aimed to gather informal feedback on their experience of using MYCaW® in practice - administering it and then using it digitally within EMIS and SystmOne to generate the data output. Feedback was collated via email response and the qualitative responses were then grouped, with the main points reflected on in this report. See Appendix E for a list of the questions asked.

3.3.2 Data collection process at SCFS frailty service

This process was as described above but using EMIS as well as SystmOne.

3.4 Data analysis

The MYCaW® and Rockwood Clinical Scale datasets were checked to ensure there were no data entry errors, and any queries on data provided were checked with data controllers before data analysis began. Each Rockwood Clinical Scale score was transformed into one of the three Rockwood frailty categories and the dataset also stratified into the frailty categories. Data which did not have follow-up scores was identified so it was not included in the quantitative analysis. The sections below describe the different stages of data analysis carried out.

3.4.1 Development of a MYCaW® Frailty Coding Framework using qualitative data

Over the past 20 years there has been a framework for analysing MYCaW® concerns, first published in 2007[15]. This framework was developed from services supporting people with cancer, and therefore parts of it were not applicable to the frailty service. To develop the new Frailty Coding Framework the following steps were taken:

1. MYCaW® concerns in this dataset were analysed using the 2007 MYCaW® framework to identify which categories were directly relevant to this dataset and which categories could be excluded.
2. Of the frailty concerns data that did not fit the original MYCaW® coding framework, content analysis was used to develop new categories.
3. The new categories were inserted into the existing supercategories and all the language of the MYCaW® frailty framework was reviewed and amended to ensure it was appropriate.

Concerns data was independently coded by two researchers. The revised decision on which categories could be removed and new categories to include were then scrutinised by a third independent researcher and any discrepancies resolved through team discussion.

3.4.2 Frequency of MYCaW® concerns

To understand the type of concerns reported by people using the frailty services, content analysis was conducted using the MYCaW® frailty coding framework on all the MYCaW® ‘concerns and problems’ reported, irrespective of whether there was follow-up data.

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[15] Seers HE, Gale N, Paterson C, Cooke HJ, Tuffrey V, Polley MJ. (2009) Individualised and complex experiences of integrative cancer support care: combining qualitative and quantitative data. Support Care Cancer, 17(9): 1159-673.

3.4.3 Follow-up qualitative MYCaW® data

The follow-up MYCaW® form has two feedback questions which people can provide open responses to; 'What other things are affecting your health' and 'What has been most important for you about the service you have received?'

These questions allow patients to identify any confounding factors which may impact on how well they respond to support from the frailty services, as well as highlighting the qualities of the services which have been most valued. For each question, data was categorised against existing categories and categories or language were refined as necessary. The frequency of responses in the categories were also analysed.

3.4.4 Are MYCaW® concerns different depending on severity of Rockwood Clinical Frailty scores?

The MYCaW® dataset was stratified according to Rockwood Clinical Frailty scores to create three subsets of MYCaW® data relating to levels of clinical frailty. The Rockwood scores were: Mildly frail (CFS score of 5 or less), Moderately frail (CFS score of 6) and Severely frail (CFS score of 7 or more). In each of the subsets of MYCaW® data, the frequency of MYCaW® concern categories were identified to establish prevalence of specific concerns in relation to clinical frailty. These subsets of concerns could then be compared across the frailty subsets and to the overall dataset of concerns to identify any particular trends.

3.4.5 Analysis of MYCaW® quantitative data

Descriptive data of the services and service users (non-identifiable demographics of 5 year age-band, gender, ethnicity, three letters of postcode) were analysed by calculating percentage frequencies of key categories of data. For MYCaW® and the Rockwood Clinical Scale, the mean changes in scores at baseline and follow-up were calculated where both baseline and follow-up data (paired data) was available. Statistical analysis was carried out to determine if the changes in scores at follow-up were significant ($p \leq 0.05$). Data was parametric, therefore a paired two-tailed t-test was used. T-tests were performed on the whole data set (the two services combined), individually for each service and then for the whole data set split three ways according to Rockwood CFS levels of Mild, Moderate and Severe. (Note, low numbers did not allow for any analysis of the Rockwood stratification for just the CC@H or SCFS service).

4.0 Results

The results section is presented in the following sections:

1. Brief analysis of the participant response rates and characteristics
2. Development of the MYCaW® Frailty Coding Framework
3. Analysis of frequency of different types of MYCaW® concerns for the whole dataset
4. Analysis of score changes for MYCaW® concerns and wellbeing ratings
5. Sub analysis of MYCaW® data according to the Rockwood Clinical Scale

4.1 Participant characteristics and response rates

Data was collected between 1.11.20 and 30.9.21. During that time, MYCaW® concerns were collected at baseline for 310 patients (257 from CC@H and 53 from SCFS). One hundred and thirteen patients had follow-up MYCaW® concern and wellbeing scores data (68 from CC@H and 45 from SCFS). Ninety-nine people had full paired Rockwood data (66 from CC@H and 33 from SCFS).

4.1.1 Which localities were the data collected from?

All demographic, MYCaW® and Rockwood data were collected from the following GP Localities: Gloucestershire (49%), Cheltenham (48%) and 3% out of area.

4.1.2 Demographics of people who provided full pre and post data (n=113)

The modal participant was 85-89 years old (33% of sample), female (60%), White (73%), and living in the GL7 postcode area (Cirencester/ Fairford in Gloucestershire, UK). (See Appendix D for demographic details).

4.1.3 Who filled in the MYCaW® forms?

Forms could be filled in by the patient, a proxy or a member of staff, and this was done in line with the guidance notes developed for the implementation of the MYCaW® tool (see methods section and Appendix A). Seventy percent of the data was collected directly from the patient, 27% from staff scribing on behalf of the patient and 2% from proxy people for the person (i.e., informal caregivers scribing on behalf of their relative or friend).

4.1.4 How was the data collected?

Ninety-one percent of the data was collected face-to-face by Health and Wellbeing Coordinators and Matrons. Six percent was collected over the telephone (using a script adapted for the project), 3% was collected over videocall.

4.2 Analysis of MYCaW® concerns and development of the MYCaW® Frailty Coding Framework

Having a coding framework enables a standardised approach to analysing individualised concerns. It also allows services to understand the breadth of concerns people expect their staff to support them with, and the proportion of these concerns that are coming in via different services. The following section details the analysis of MYCaW® concerns for the combined dataset of n=310 patients. Patients had the opportunity to list up to two concerns, hence the total number of concerns reported and analysed was 576.

The researchers used an established content analysis protocol to analyse the patient concerns, which involved two researchers independently categorising the data according to the existing MYCaW coding framework. This method of analysing MYCaW® data is further detailed in Polley et al. (2007)[16]. For this project, the researchers went on to create a new frailty specific framework by reviewing the concerns that didn't fit into the existing framework and independently creating new potential categories. The new categories were reviewed by a third researcher and any discrepancies discussed until agreement was reached. The changes made to the original concerns framework were as follows: from the 37 original categories in the existing framework, 23 categories were taken out, leaving 14 core categories common to both original and frailty data sets. The frailty coding framework analysis generated 22 new categories to be added, resulting in 36 categories in the new MYCaW Frailty Coding Framework. (See Appendix E for details of all the original and revised codes).

Once the concern categories had been identified and agreed, they were grouped into overarching themes which we call supercategories and a framework finalised. Again, a review of the supercategories was carried out by the research team and a final list of supercategories was established. One whole supercategory from the original coding framework was removed (S3 - Hospital Cancer Treatment Concerns), and two new supercategories were generated; S3 - Healthcare and service provision concerns, and S6- Concerns about a carer or partner/family member. The latter was derived from codes from the MYCAW coding framework for carers[17].

The final framework includes a total of 36 categories organised into six supercategories, as detailed in Table 1. The accompanying codebook (accompanying this report) details each category and corresponding definitions, enabling other people analysing subsequent MYCaW® data to categorise data in the same way.

The key supercategories of concerns include a range of psychological and emotional concerns, concerns relating to physical conditions, healthcare and service provision concerns, concerns relating to wellbeing, concerns about practical aspects of life, and concerns relating to supporters and carers.

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[16] Polley MJ, Seers HE, Cooke HJ, Hoffman C, Paterson C. (2007) How to summarise and report written qualitative data from patients: a method for use in cancer support care. Support Care Cancer; 15(8): 963-71. https://doi.org/10.1007/s00520-007-0283-2

[17] Jolliffe R, Collaco N, Seers H, Farrell C, Sawkins MJ, Polley MJ. (2019) Development of Measure Yourself Concerns and Wellbeing for informal caregivers of people with cancer-a multicentred study. Support Care Cancer; 27(5):1901-1909. doi: 10.1007/s00520-018-4422-8.

Supercategory	Category
S1 - Psychological and Emotional Concerns	Confidence issues
	Depression/low mood
	Emotional problems
	Fear and anxiety
	Sleep problems
	Support
	The future
	Loneliness
	Dementia/memory problems/confusion
	Lack of motivation
S2 - Physical Concerns	Diabetes/pre-diabetes
	Pain/aches
	Other physical problems/conditions
	Poor energy levels/fatigue
	Weight changes
	Continence
	Sight/vision
	Mobility
	Falls
	Breathing problems
S3 - Healthcare and service provision concerns	Care and support information (general)
	Healthcare provision and support
	Other services
S4 - Concerns about Wellbeing	Exercise/Physical activity
	General wellbeing
	Nutrition and diet
	Getting out
	Independence
	Social interaction
	Finances
	Housing

S5 - Practical Concerns	Managing the household/assistance with daily living
	Transport
	Other practical concerns
S6 - Supporter/Carer/Family concerns	Support to partner/carer/family member
	Worries about partner/supporter/family member health

Table 1: MYCaW® Frailty Coding Framework

4.3 Analysis of frequency of MYCaW® concerns for the whole dataset

Using the Frailty Coding Framework above, 546 concerns from n= 310 patients were organised. There were 13 people who stated that they had no concerns and 17 instances where people's data was not possible to code into a category as the response was unclear or too abstract. Therefore, upon cleaning through the data, 30 responses were excluded before coding the data.

The frequency of concerns in each supercategory is shown in Figure 1 below as a percentage. As can be seen clearly, physical concerns related to just over a third of the data. These concerns relate to physical conditions people are experiencing.

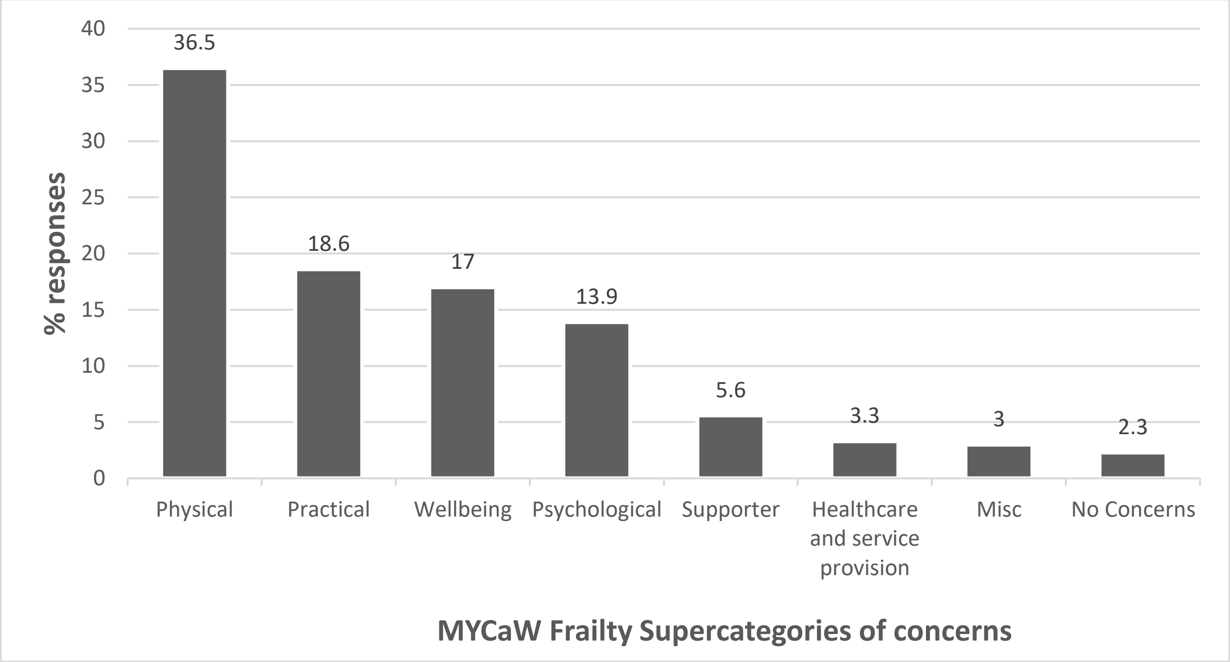


Figure 1: Percentage of concerns in each MYCaW® supercategory

4.4 Understanding what MYCaW® concerns were reported in each supercategory

This section reports the frequency of MYCaW® categories that were reported in each of the supercategories displayed above. Analysing the frequencies at this level helps to identify if there are any key types of concerns that services could be supporting or whether there is a general spread of concerns. In each case we have highlighted the top three concerns in each supercategory, the definitions of the other categories can be found in the accompanying framework document.

4.4.1 What concerns were reported in the physical concerns supercategory?

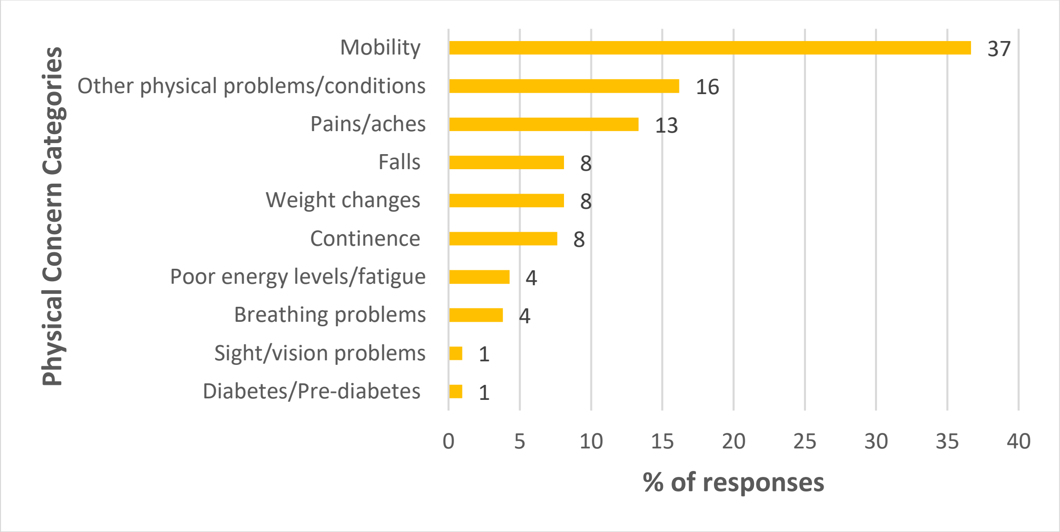


Figure 2: Analysis of MYCaW® concerns in the physical concerns supercategory

Overall, 36.5% of all concerns reported were in this category. As shown in Figure 2, physical concerns most frequently related to 'mobility'. This included any concerns that referenced inability to physically move around, using aids to move around, balance, ability to open/close things or moving around/getting in/out of bed.

***"I would like to improve my mobility so that I can walk to the end of the garden on a nice day."* Patient**

***"My left knee gives way which affects my walking."* Patient**

***"I want to get back to walking with my 2 sticks. At the moment I don't feel safe with them."* Patient**

‘Other physical problems/conditions’ related to general expression of concerns about a person’s condition or comorbidities. It may also refer to a person’s understanding of their own condition.

“I want to get rid of the itching all over my body.” **Patient**

“My feet - Both. During my MOT, nurse said she thought I had gout.” **Patient**

“Understanding my Huntingdon’s.” **Patient**

The third most frequent category was ‘pains/aches’. This related to concerns about feelings of pain, discomfort or aches anywhere in the body, general muscular aches and pains or references to pain management.

“To get back pain sorted.” **Patient**

“I would like the pain in my left shoulder and leg to be better.” **Patient**

“Pain management of knee and back affecting mobility.” **Patient**

4.4.2 What concerns were reported in the practical concerns supercategory?

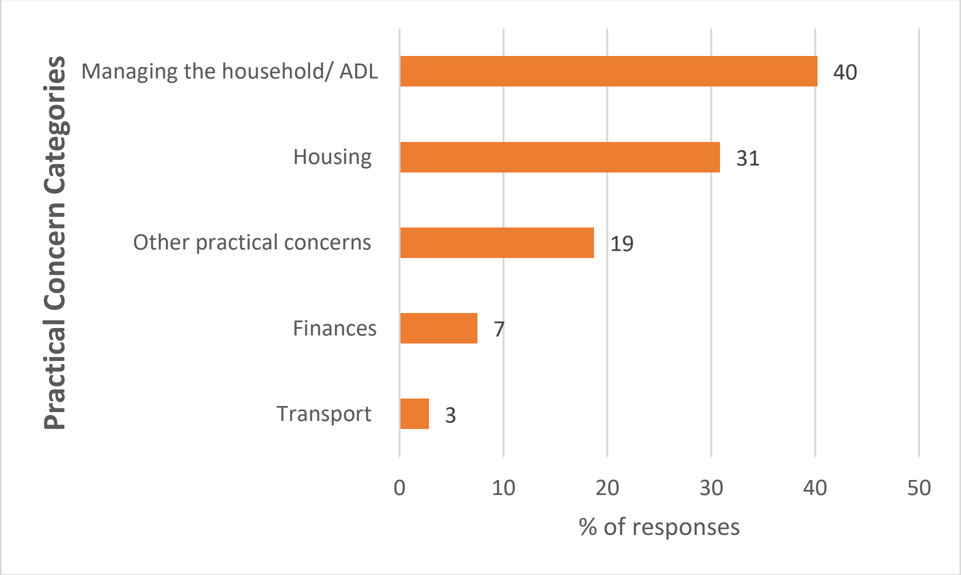


Figure 3: Analysis of MYCaW® concerns in the practical concerns supercategory

Figure 3 shows the 18.6% of all concerns that were in this supercategory. Of the five categories relating to practical concerns, ‘managing the household and support with activities of daily living’ was most frequent. This may include needing help with cooking, administration, paying bills, cleaning, bathing, digital access, using a computer, dressing, help getting in and out of bed or access to a cleaner.

***"Help with bathing (bath equipment) and having a shower."* Patient**

***"Getting help with cleaning."* Patient**

***"Help with shopping and household duties."* Patient**

The 'housing' category includes concerns about adaptations in the house, or concerns about issues with selling or buying property, land issues, moving to a home, having to leave home, the desire to remain at home, and issues with furniture.

***"Having to leave my home if I cannot manage."* Patient**

***"Worried about future housing plan."* Patient**

***"I would like my bathroom adjusted to a wet room to assist me with my personal hygiene."* Patient**

'Other practical concerns' included references to concerns about managing things outside of the house e.g., arranging funerals, wheelchair access to shops, access to medication and attending appointments.

***"I would like a wheelchair so that my family can take me out."* Patient**

***"Sorting out my tablets."* Patient**

***"Sort out all this paperwork. My husband used to always do the paperwork and now he is gone, I don't know where to start."* Patient**

4.4.3 What concerns were reported in the wellbeing concerns category?

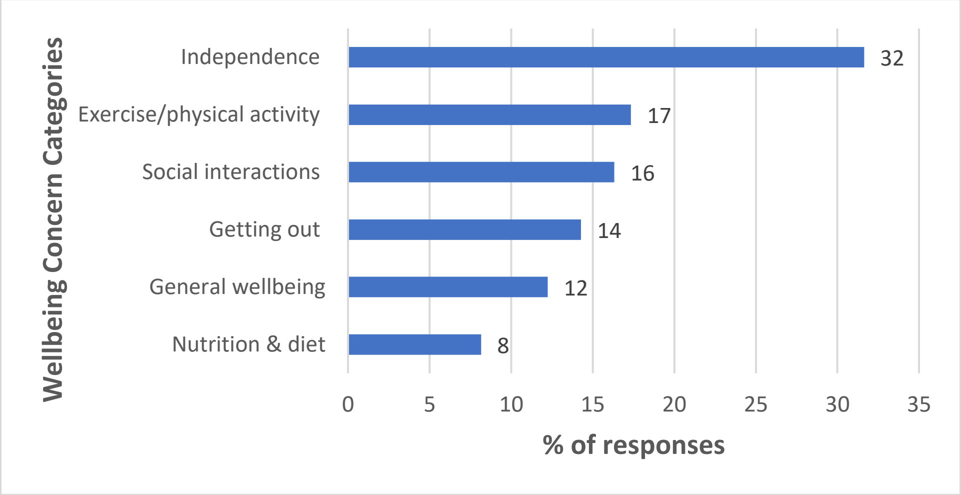


Figure 4: Analysis of MYCaW® concerns in the wellbeing concerns supercategory

Seventeen percent of all concerns reported were in this category. The most frequent concerns related to 'independence'. This included any reference to being able to get around on one's own or do an activity by oneself e.g., cooking or washing hair. It also includes concerns about loss of independence.

“I treasured my independence and its learning how to cope with loss of independence.” **Patient**

“I missed going to the shop and doing my own shopping.” **Patient**

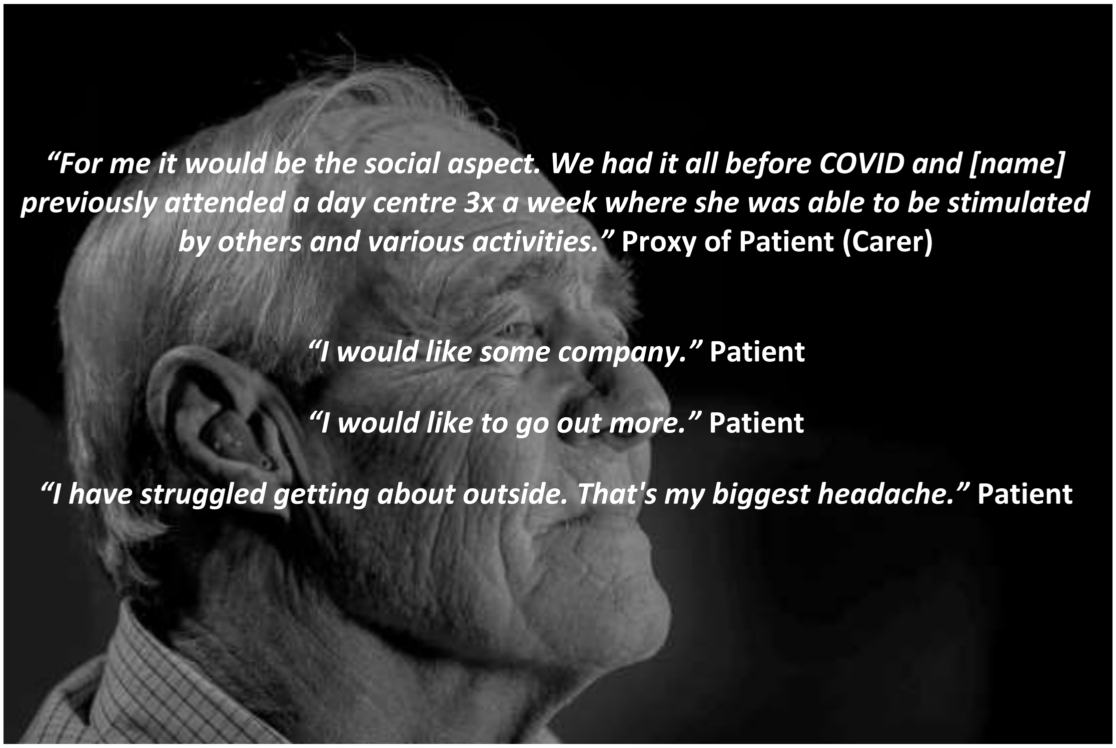
“I would like to be able to wash my own hair.” **Patient**

The other two most frequently mentioned categories were ‘Exercise / physical activity’, and ‘Social interactions’. The ‘exercise/physical activity’ category included concerns about starting to exercise and being more physically active, returning to exercise, or doing more exercise. It also includes negative comments about not being able to do exercise at the moment, or not knowing what exercise to do that is safe. Finally, it includes comments about building strength, keeping active, motivation and receiving physio support.

“I should work towards taking more exercise […].” **Patient** ***“I would like some physio for my legs and my left arm (and stairs).”*** **Patient**

“To have more strength in my legs.” **Patient**

The concerns in the ‘Social interactions’ category include concerns about being part of social groups, wanting to interact/talk with others, befriending and hobbies. The social interactions category was split up from the ‘getting out’ category as the social interactions may related to people doing activities and having social interaction in their home or via phone or computer. The ‘getting out’ category related to where people specifically referred to wanting to get out the house (safely), get outside, wanting to get out more or go out.



“For me it would be the social aspect. We had it all before COVID and [name] previously attended a day centre 3x a week where she was able to be stimulated by others and various activities.” **Proxy of Patient (Carer)**

“I would like some company.” **Patient**

“I would like to go out more.” **Patient**

“I have struggled getting about outside. That's my biggest headache.” **Patient**

4.4.4 What concerns were reported in the psychological and emotional concerns category?

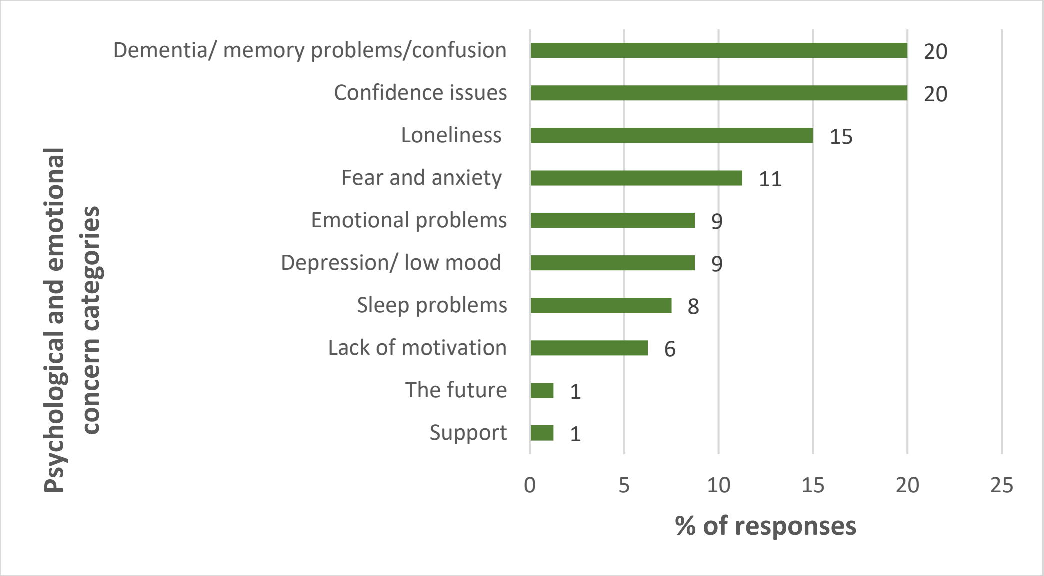


Figure 5: Analysis of MYCaW® concerns in the psychological and emotional concerns supercategory

Overall, 13.9% of all reported concerns were in this category. The top two concerns were relating to ‘dementia/memory/confusion’ and ‘confidence issues’. The ‘dementia/memory/confusion’ category captured references to dementia, experiencing memory problems (which may be referred to as ‘muddles’) or confusion.

“My short-term memory is not as good.” **Patient**

“Bothered about the 'muddles'. I've got the messes.” **Patient**

“My Memory - I forget almost straight away when [name] tells me something. I just accept it.” **Patient**

The category on ‘confidence issues’ include direct references to confidence or self-confidence. Often people didn’t specify more than just stating confidence. Where they did report more detail, this included confidence in the future, with walking, or confidence carrying out an activity. Some references were directly identifying lack of confidence.

“Building up confidence when walking outside.” **Patient**

“[…] getting my confidence back to do stuff that I used to do. I am losing confidence and power to walk like I did.” **Patient**

“Confidence when going to the hospital […].” **Patient**

The 'loneliness' category was straightforward and included any references to feeling lonely or isolated.

"Feeling isolated and lonely." **Patient**

"Loneliness - I want someone to talk too, go for short walks." **Patient**

"Feeling lonely and isolated as husband has Dementia and conversation very limited."

The 'fear and anxiety' category included any concerns with a direct reference to being fearful, anxious or scared. This could include fear or anxiety around waiting for results of medical investigations.

"Find out what is making me so fearful when I go out." **Patient**

"[…] I feel sorry for myself and I feel scared." **Patient**

"Anxiety in general but it is also impacting on my mobility confidence" **Patient**

4.4.5 Understanding Supporter/Carer/Family concerns

Only 5.6% of the overall dataset reported concerns in this supercategory. Two thirds of these concerns were the patient having concerns about the carer being able to provide support.

"What I need help with is providing a sufficient level of care for my wife." **Patient**

"I'd most like help with looking after [name] properly and sorting out [name's] incontinence." **Patient**

"Supporting [name] to support me." **Proxy**

It also included the patient not wanting to burden others or ask for help, or the desire for the patient to be able to do normal things with their partner e.g., Sleep in the same bed.

"Worried about my son's pain due to his arthritis." **Patient**

"Worry about my wife - left here on her own […]." **Patient**

4.4.6 Understanding healthcare and service provision concerns

This category only had 3.3% of concerns from the whole dataset, which equates to approximately 20/546 concerns. Approximately 12 concerns related to healthcare provision and support, which included concerns about advice from healthcare professionals on medications, medical observations, lack of support, communication between health providers and desire for support. Approximately 6 concerns related to wanting more information or having someone to ask for support/guidance/advice, or availability of specific advice e.g., about respite care.

"I want to get back to [name of service]." **Patient**

"I would like some support to understand what care and support is available to remain at home". **Patient**

"I would like better communication between GP and other specialities." **Patient**

4.4.7 What were the top 5 categories of concerns for the whole dataset?

Understanding the breakdown of categories in each supercategory is useful to get a deeper understanding of the range of concerns being reported. However, it is also important to know what the top concerns are across the dataset to understand what aspects of service provision may need prioritising. Forty percent of all concerns were made up of the five categories in Table 2 below. (The colours of rows match colours of graphs above and colours of supercategories in the MYCaW® Frailty Coding Framework).

Category	**Number of concerns identified**	**% dataset n=546**
Mobility	**77**	**14**
Managing household and activities of daily living	**43**	**8**
Other physical problems	**34**	**6**
Housing	**33**	**6**
Independence	**31**	**6**

Table 2: Most common concerns reported across the dataset using the MYCaW® Frailty Coding Framework

4.5 How well do the frailty services address people's concerns and support their wellbeing?

When people report their MYCaW® concerns they also rate the severity of each concern on a scale of 0-6. This is repeated at a designated follow-up time point and below we examine whether concerns scores reduce in severity at follow-up. People also rated their wellbeing at each timepoint - again we examine this score across the two time points.

The quantitative data was analysed if there was a baseline and follow-up score for a patient. There were 113/310 people who had follow-up data that we could use. Therefore, the analysis represents 36% of the overall dataset and caution should be exercised when interpreting the data. Usually, a representation of 80% of the dataset or more is needed to have confidence that the overall interpretation of data would remain the same, even if more data were collected.

The change in mean scores for MYCaW® concerns (1 and 2), wellbeing and MYCaW® profile were all statistically significant ($p<0.001$). This shows that the service provided is supporting people's concerns and improving their wellbeing. As mentioned above, this only relates to the scores we were able to analyse - further data collection is needed to understand if this conclusion is true for a greater proportion of people using the service. It was noted that some people died before follow-up was conducted but data wasn't collected on how many people sadly passed away.

MYCaW® scores (n=113)	**Mean baseline score (SD)**	**Mean follow-up score (SD)**	**Mean Score change (p value)**	**% of sample with minimal important improvement**	**% of sample with minimal important deterioration**
Concern 1	4.6 (1.7)	2.9 (1.9)	-1.6 (p<0.001)	63.2%	7.9%
Concern 2	3.2 (2.4)	2.3 (1.9)	-0.8 (p<0.001)	38.6%	5.3%
Wellbeing	3.2 (1.6)	2.6 (1.4)	-0.6 (p<0.001)	47.4%	13.2%
Profile	3.6 (1.5)	2.6 (1.5)	-1.1 (p<0.001)	64.9%	7%

Table 3: Summary of MYCaW® score changes (n=113)

The dataset was analysed for each service separately as shown in Tables 4 and 5 below. As stated before, the small n values mean that this data is a preliminary finding and further data collection is needed to firm up conclusions. The analysis currently shows that both services are showing significant improvements in MYCaW® concerns and wellbeing. There are small variations in the degree of score changes but there is not enough data for each service to know yet if those difference are real or would even out with a higher n value.

MYCaW® scores CC@H (n=68)	**Mean baseline score (SD)**	**Mean follow-up score (SD)**	**Mean Score change (p value)**	**% of sample with minimal important improvement**	**% of sample with minimal important deterioration**
Concern 1	4.5 (1.8)	3.1 (2.1)	-1.4 (p<0.001)	58.8%	8.8%
Concern 2	2.7 (2.6)	1.8 (2)	-1.0 (p<0.001)	42.6%	4.4%
Wellbeing	3.2 (1.7)	2.6 (1.5)	-0.6 (p<0.001)	52.9%	16.2%
Profile	3.5 (1.7)	2.5 (1.5)	-1 (p<0.001)	64.7%	4.4%

Table 4: Summary of MYCaW® score changes for CC@H (n=68)

MYCaW® scores SCFS (n=45)	**Mean baseline score (SD)**	**Mean follow-up score (SD)**	**Mean Score change (p value)**	**% of sample with minimal important improvement**	**% of sample with minimal important deterioration**
Concern 1	4.6 (1.6)	2.7 (1.7)	-1.9 (p<0.001)	66.7%	6.3%
Concern 2	4.4 (1.4)	3.4 (2.2)	-0.7 (p<0.001)	31.3%	6.3%
Wellbeing	3.3 (1.5)	2.6 (1.1)	-0.6 (p<0.001)	37.5%	8.3%
Profile	4.2 (1.5)	2.8 (1.6)	-1.4 (p<0.001)	62.5%	8.3%

Table 5: Summary of MYCaW® score changes for SCFS (n=45)

To understand how impactful the score changes are, we can analyse the proportion of score changes that reach a minimal important difference threshold. This means the level of score change will have a clear impact on the person. The last two columns of Tables 3, 4 and 5 show that this can be an improvement in score but also a deterioration. In the 113 sets of scores analysed, 63.2% of concern 1 scores met the minimal important difference for improvement, 7.9% for deterioration. There is therefore an overall clear direction of improvement, and the majority of people are having their unmet needs and concerns addressed and supported.

The wellbeing of people also improved overall, with a statistically significant score change which is on par with the level of change in wellbeing seen in other MYCaW® datasets. Nearly half of patients met the minimally important threshold for improved wellbeing and 13.2% met this threshold for deterioration. It must be noted that the dataset is made up of people who are at times very poorly and may be at the end of life, therefore expectations for improved wellbeing scores need to be interpreted with this in mind.

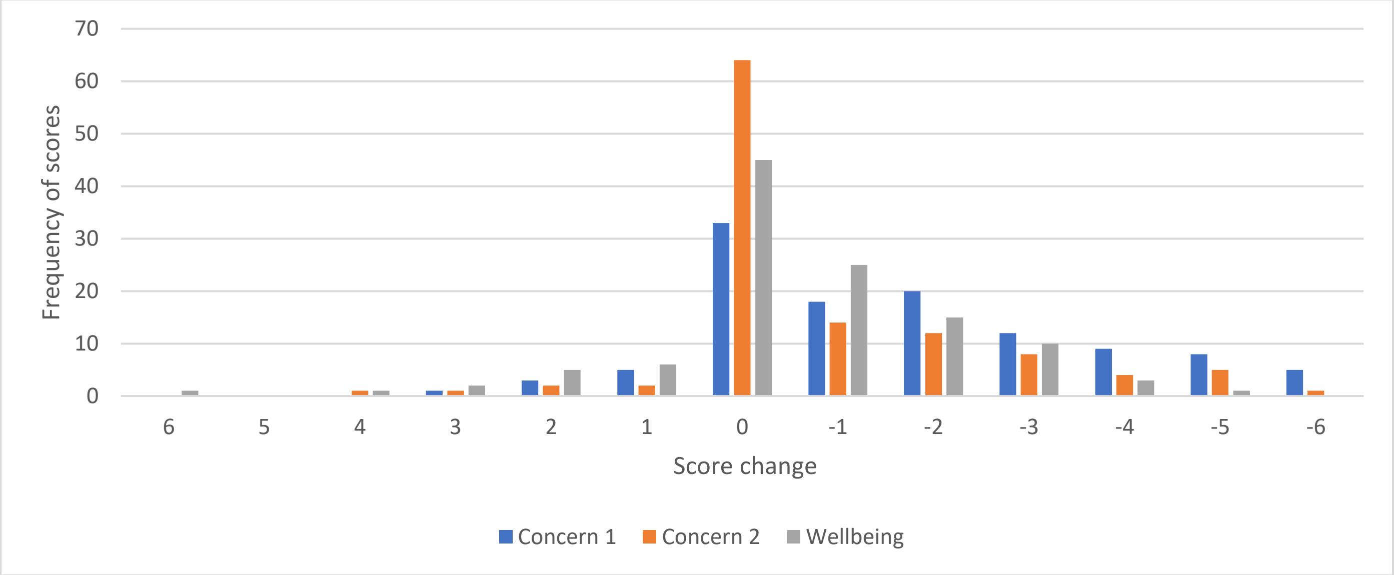


Figure 6: Change in MYCaW® concern and wellbeing scores for all data. A reduction in score denotes a reduction in severity and therefore an overall improvement.

Figure 6 has plotted out the frequency of score changes. “0” denotes that the scores were the same at baseline and follow-up. In a population where people are already very ill, no change can be interpreted in different ways. It could mean that the service didn’t impact on the person, or it could mean stability is being maintained. This is an important distinction to consider if the sample includes people who have conditions that can only deteriorate and not improve.

Figure 6 further shows that the vast majority of score changes show a decrease in severity and therefore an improvement in a situation. The majority of improvements are by 1 or 2 points on the MYCaW® scales and again this is in line with other MYCaW® datasets. The Figure also shows that very few of the scores are deteriorating. It would be possible to further audit these cases to understand what has contributed to the deterioration – whether there is anything the services could be doing better or whether this is down to external factors. The below section on ‘other things affecting your health’ will detail what other external factors were reported.

4.6 What other things are affecting people’s health?

On the follow-up MYCaW® form, people can state if there is anything else happening in their life that is having an effect on their health. As with the concerns, we have an established set of categories used to organise the data. These are explained in detail in the accompanying code book for the Frailty Coding Framework and are briefly described here. Within each supercategory, individual categories may have a positive impact or a negative impact, hence the category nomenclature. (Note, the frailty data set generated an updated set of categories – with 17 in the original framework, losing 10 categories, and adding six new ones in the context of frailty. See Appendix E for details).

Sixty people out of n=546 reported additional things affecting their health. As per the frequencies reported in Table 6 below, the biggest additional impact was a negative impact on people from health issues they are experiencing.

"Infections and delirium." **Patient**

"I have a pain in my head which is bothering me." **Patient**

"I am getting weaker on my legs and my knees feel weak." **Patient**

Supercategory	**Category**	**Frequency**
Awareness of wellbeing	Taking exercise (positive)	**2**
	Awareness of own wellbeing (positive and negative)	**4**
Major life events	Negative change of environment	**3**
	Bereavement (negative)	**1**
Social support	Increased social support (positive)	**1**
	Family (positive)	**1**
	Partner (positive and negative)	**5**
Health issues	Negative	**20**
	Positive	**5**
	Neutral	**1**
	Receiving support from health professionals (positive and negative)	**4**
Unclear	Any responses which we could not interpret	**10**

Table 6: Frequencies of categories for the question "What other things are affecting your health"?

4.7 Does the severity of the Rockwood Clinical Scale score affect MYCaW® concerns or wellbeing?

The next section of the results looks to see if there are any trends or observations of people's types of MYCaW® concerns, or level of MYCaW® score changes, according to the severity of frailty they are experiencing. The severity of frailty was designated using the Rockwood Clinical Scale score.

The overall mean Rockwood Clinical Scale score was 5.3 for both first and follow-up measurements (or rating someone as 5 on the scale which is mildly frail) - see Figure 7 below. Of the 99 people who had Rockwood scores, 49% were designated as mildly frail, 30% moderately frail and 21% severely frail.

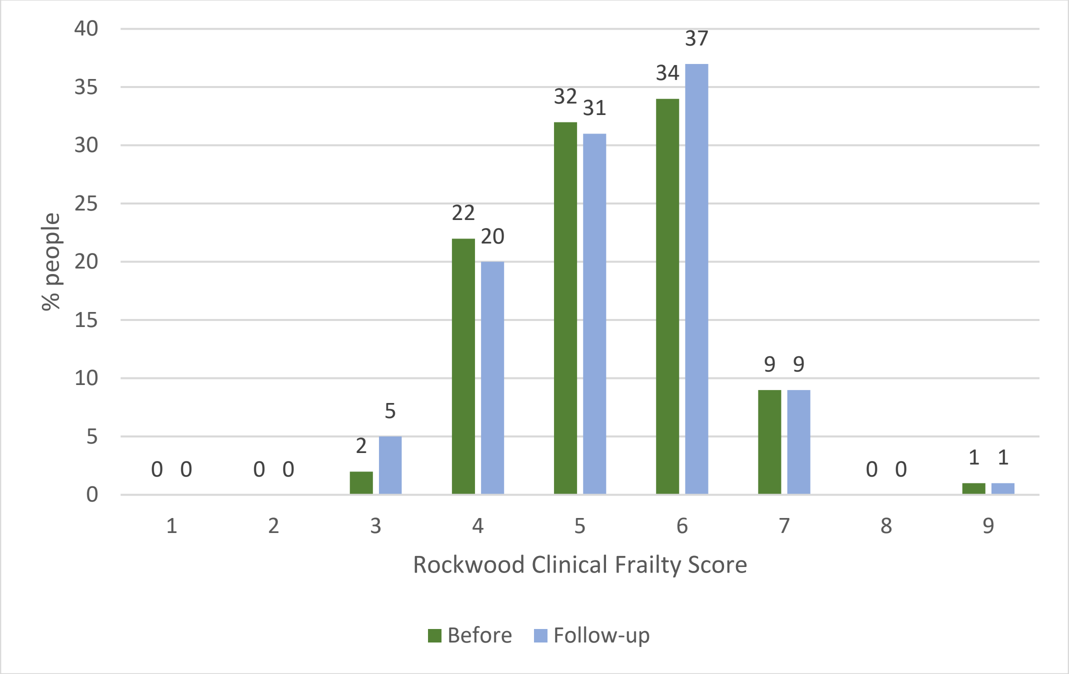


Figure 7: Average Rockwood Clinical Frailty Scores comparing before and follow-up

Interestingly, the mean Rockwood score for CC@H was 4.9 (both first and follow-up sores, n=66), and the mean for SCFS was 6.0 (first) and 5.9 (follow-up, n=33). This shows that the SCFS is looking after people who are frailer on the scale, although more data collection is needed to confirm this finding.

The whole of the MYCaW® dataset was stratified according to the frailty categories and the data is presented below. It should be noted that the number of people in each frailty category is low to do much statistical analysis, so these data are preliminary findings and will need backing up with more data collection and analysis.

First the MYCaW® score changes for each frailty category were calculated – see Table 7 below. All score changes were statistically significantly improved in people with mild frailty. For people with moderate and severe frailty, the concern scores were statistically significantly improved but the wellbeing was not. This could be due to the low amount of data in the categories, it could be due to people having severe illness affecting quality of life which isn't going to improve, or it could be that the service didn't meet their needs enough to improve wellbeing – only further data collection and analysis will be able to answer that.

Rockwood category	MYCaW® Scores	Mean baseline score (SD)	Mean follow-up score (SD)	Score change and significance	% of sample with minimal important improvement in score	% of sample minimal important deterioration in score
MILD ROCKWOOD 1-5 (n= 56)	Concern 1 Concern 2 Wellbeing Profile	4.7 (1.8) 3.1 (2.6) 3.3 (1.7) 3.7 (1.6)	3.2 (1.9) 2.1 (2.1) 2.5 (1.3) 2.6 (1.5)	-1.5 (p<0.001) -1.0 (p<0.001) -0.8 (p<0.001) -1.1 (p<0.001)	57.1% 46.4% 53.6% 67.9%	8.9% 5.4% 12.5% 8.9%
MODERATE ROCKWOOD 6 (n= 34)	Concern 1 Concern 2 Wellbeing Profile	4.1 (1.9) 3.0 (2.4) 3.1 (1.5) 3.4 (1.5)	2.6 (2.0) 2.3 (2.3) 2.5 (1.6) 2.5 (1.6)	-1.5 (p<0.001) -0.6 (p<0.001) -0.5NS -1.1 (p<0.001)	64.7% 29.4% 41.2% 55.9%	5.9% 8.8% 14.7% 5.9%
SEVERE ROCKWOOD 7 plus (n= 24)	Concern 1 Concern 2 Wellbeing Profile	4.9 (1.3) 3.8 (2.1) 3.3 (1.7) 4.0 (1.3)	2.8 (1.8) 2.6 (2.8) 2.9 (1.2) 2.8 (1.6)	-2.1 (p<0.001) -0.9 (p<0.001) -0.4 NS -1.5 (p<0.001)	75.0% 33.3% 41.7% 70.8%	8.3% 0% 12.5% 8.3%

Table 7: MYCaW® scores split by the Rockwood Clinical Scale categories of severity

4.8 Do Rockwood definitions of what people are able to do with mild/ moderate and severe frailty correlate with MYCaW® concerns supercategory patterns?

Figure 8 shows the order of the frequency of MYCaW concern codes stratified by Rockwood scores.

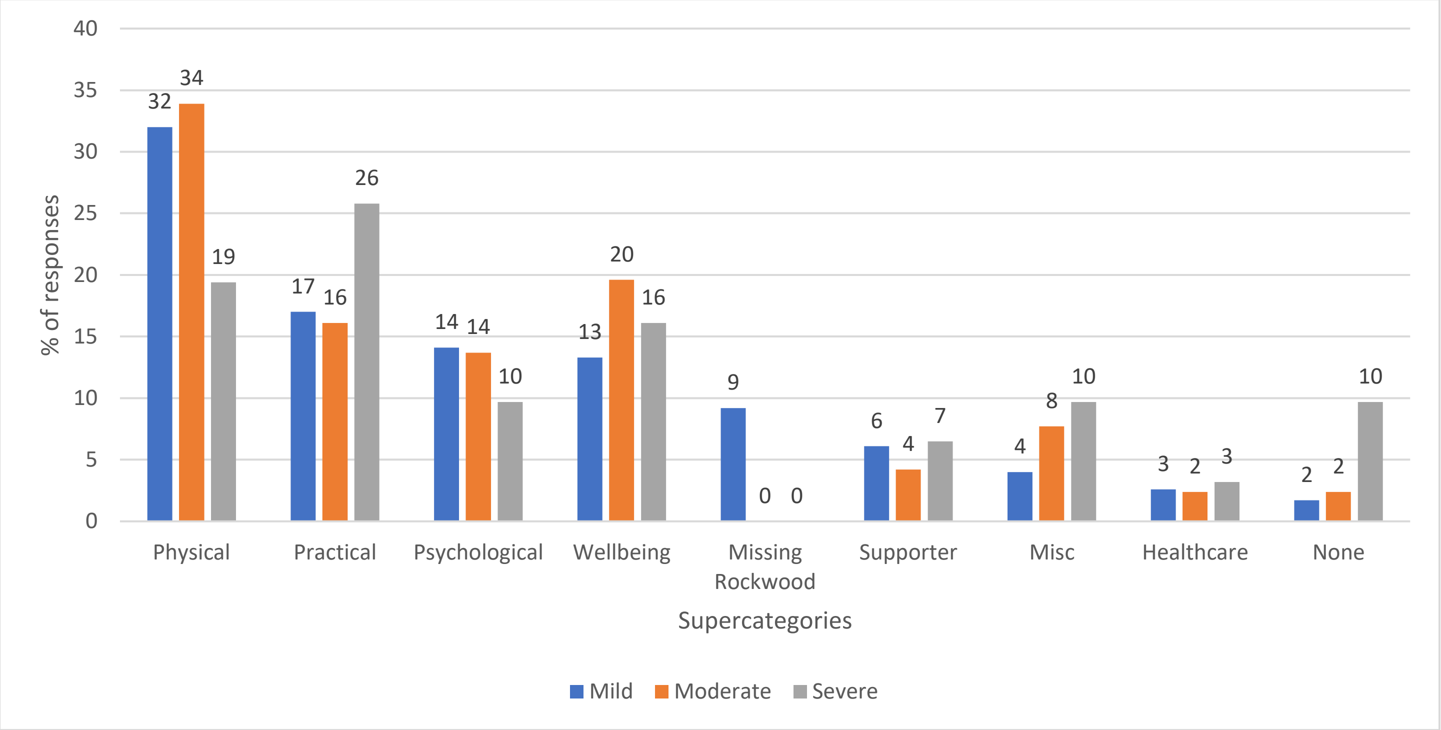


Figure 8: The percentage scores of MYCaW® concerns data stratified by Rockwood Clinical Frailty Scores

Mildly frail **(CFS score of 5 or less)** These people often have more evident slowing, and need help in high order IADLS (instrumental activities of daily living – e.g., finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework. MYCaW® showed top concerns were physical (top concern mobility issues), followed by practical (top concern ADL), then wellbeing (top concern independence).

Moderately frail **(CFS score of 6)** People need help with all outside activities and with keeping house. Inside, they often have problems with stairs and need help bathing and might need minimal assistance (cuing, standby) with dressing. MYCaW® showed top concerns were physical (top concern mobility), then wellbeing (top concern independence), followed by practical (top concern ADL).

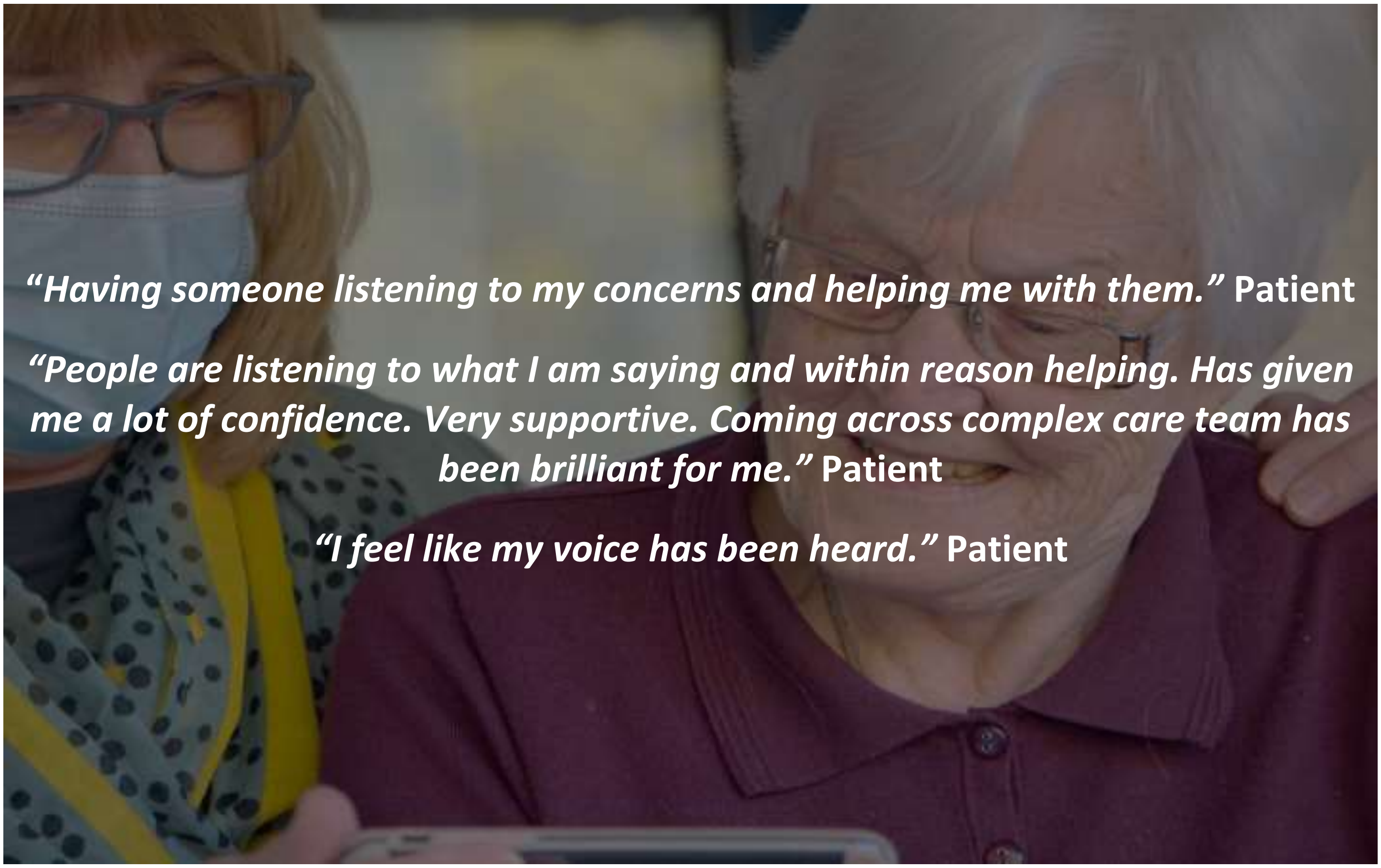
Severely frail **(CFS score of 7 or more)** Completely dependent for personal care, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying within six months. MYCaW® showed top concerns were practical (ADL), then physical (mobility) then wellbeing (independence).

Note – Analysis of qualitative data for each service has not been undertaken due to the small dataset. Also, the two services are very similar in their remit, therefore the data can be combined with meaning.

4.9 Patient experience of the service

To understand what patients find important about the service they have received, they are asked to identify the most important aspects on their follow-up MYCaW® form. Generally, these are very positive comments, but the question is worded to allow for negative feedback as well. The categories below were first published in Polley et al 2007. As with the coding framework for MYCaW® concerns, the existing categories were used where relevant and independence was inserted (from the original 11 categories, four were removed and two added for the frailty data, see Appendix E for details).

Ninety-nine people provided feedback and by far the most frequent feedback was about the positive support and understanding that patients received from the frailty services.



"Having someone listening to my concerns and helping me with them." **Patient**

"People are listening to what I am saying and within reason helping. Has given me a lot of confidence. Very supportive. Coming across complex care team has been brilliant for me." **Patient**

"I feel like my voice has been heard." **Patient**

Some people mentioned that they appreciated their improved wellbeing.

“Anxiety has improved with Matron’s support.” **Patient**

“I feel the team have all made such a difference to mine and my husband’s quality of life.” **Patient**

Others mentioned the confidence they had in the service and the staff providing the service.

“Frailty team always there to help and assist, especially when I struggle to get through to Doctors.” Patient

“[name] feels during the input from Complex care team [name] feels it had given his confidence a boost with his mobility and general self-care.” Other

“I feel that having [therapist 1] and [therapist 2] visiting three times a week has really improved my mobility. They both motivated me to do the exercises even though I did not always want to do and I can tell that this has help with my increased confidence and my increased mobility.” Patient

Categories	**Frequency**
Support and understanding received	**64**
Access to services/support	**4**
Confidence in staff	**6**
Care and kindness	**2**
Independence	**7**
Wellbeing	**9**
Appreciation of service and its resources	**5**
Negative feedback	**1**

Table 8: Frequency of codes per category for the question “What has been most important for you?”

The full description of the categories is in the accompanying Frailty Coding Framework document.

4.10 Staff experience of using MYCaW®

Five people provided their feedback via email about the practical experience of administering and using MYCaW® as a member of staff (see Appendix F for questions asked). These five people were four Community Matrons and one Assistant IT Training Manager. The responses helped capture key learning which can be used in the future to enable MYCaW® to be better used and embedded into administrative systems. We are also very grateful for all staff members' hard work on implementing the MYCaW® tool.

Were there any issues with collecting data using MYCaW®? (Practical data collection issues, wording, instances it didn't work) Four out of five respondents stated no issues, with one person mentioning that the simplicity of the tool was good. However, one person did note that the set out was not "very user friendly and I do find myself having to repeat the scoring to patient"

Were there any issues with embedding the MYCaW® data collection in your digital systems? (e.g., EMIS/ SystmOne? Or any other systems you use) Three out of five stated that there were no issues here, with one saying it was all "quite straightforward". However, one person added that there was "Potential for confusion with paper and electronic processes running in tandem. Also, unable to capture electronically consent to information sharing – sometimes forget to record so would be good to include this in electronic questionnaire." In terms of embedding MYCaW® within EMIS and SystmOne, the feedback was that had been straightforward.

Were there any issues with creating or using templates for MYCaW® in your digital systems? Four out of five stated that there had not been any issues as this was not relevant to their role. Only the Assistant IT Training Manager stated that there had been problems with the clinical template creation in EMIS: *"Creating the EMIS clinical template and search were very challenging based on the lack of appropriate SNOMED codes. Proxy codes were used to mimic Concern or Problem 1 and Concern or Problem 2 which were also being used by practices for other purposes. The initial design of the template and search has gone through several refinement iterations to get to a position where the data extracted is accurate and meaningful. The SystmOne MYCaW® questionnaire was created by GHC and as it doesn't require codes I would assume it was an easier process to replicate the MYCaW® tool in SystmOne."*

Were there any issues with creating reports for MYCaW® data to output to Meaningful Measures? Only the IT training Manager provided this feedback showing the hard work involved in creating the data reports for export to Meaningful Measures: *"SystmOne can generate a MYCaW® questionnaire export report, but this doesn't include demographic data. A separate demographic search was created to include partial postcode and ethnicity. Both reports need to be run, exported to Excel, and merged using a macro tool."*

What was the overall experience of using the MYCaW® tool in your work? (Does the tool fit your work needs, patient needs?). All respondents found the use of MYCaW® to be a positive experience e.g., *"It's very simple to use"* (Community Matron). Another Community Matron reflected*: "I have found it very useful as a focus on what we are trying to achieve with and for the patient. It will bring a drifting situation back to our original assessment objectives and goals."*

Another Community Matron did mention that there were issues with the timing of the tool which was good learning to take away: *"Timings of questionnaires can be very difficult. A lot of the time the scene we walk into on first visit just isn't appropriate. Can take a couple of visits to gain trust by which time you may have started to work on some of the issues so you end up back tracking. Trying to find ways of measuring at right time."*

5.0 Discussion

The aim of this work was to implement the person centred MYCaW® questionnaire into the frailty services and to understand what the MYCaW® data can capture in relation to the breadth and impact of the frailty services.
Overall, the data shows a very positive picture of the services provided, with many patients appreciating the support and understanding that is shown to them.

5.1 What do the MYCaW® score changes show?

Despite people experiencing moderate or severe frailty, on the whole their designated MYCaW® concerns were still being met. This was demonstrated by the statistically significant changes in MYCaW® scores and high percentage of people who had meaningful levels of score changes.

The levels of wellbeing were also significantly improved for the whole data set. When that data was stratified for frailty severity, only people experiencing mild frailty had a statistically significant improvement in their wellbeing. It is an important point to note here that the whole dataset has a low n value for the quantitative analysis. Therefore, when the data set starts to be split up either for the services or for frailty severity, the results should be viewed as an emerging trend only. Further data collection to augment this existing dataset would be a valuable continuation of this project, especially to further understand how the severity of frailty is impacting on people's wellbeing levels over time.

There was no change in the Rockwood scores over time, whilst MYCaW® has been able to show improvements and deteriorations to people's concerns and wellbeing. Therefore, MYCaW is adding a dimension on personalised information that was not otherwise being captured. Importantly, this information can be used by healthcare practitioners to improve the personalised nature of the support they provide.

5.2 What does the qualitative data show?

The qualitative analysis of MYCaW® concerns have provided a rich picture of the breadth of concerns that are important to frailty patients. The existing MYCaW® coding framework was revised to become bespoke for this setting and has shown that concerns most frequently related to mobility, managing the household and ADLs, physical problems, housing and independence. On the face of it, these make sense coming from people who are experiencing frailty.

Unlike the quantitative dataset, where the n value was on the low side, there were 547 concerns stated which enabled clear categories to be identified. It is important for the staff now to review the concerns and decide if they feel these represent what they generally hear in discussions with clients and to reflect on how the pandemic is impacting on the frequency or type of concerns being recorded. More data collection may identify a few more categories, but it is likely that the vast majority of concerns have now been identified for the Frailty Coding Framework. It is possible however that the frequency of concerns may change if MYCaW® data is collected in different geographical locations or by different services.

By reviewing the range and frequency of concerns, the frailty services can compare and see if there is anything that is beyond what their service can provide, or whether the frequency of concerns is what they expected. One important observation about the concerns was the number of people reporting that they had no concerns - this was particularly noticeable in the group who had the most severe frailty.

The follow up MYCaW® form also asked if there were other things happening in people's lives that were affecting their health. Under 10% of the cohort reported additional things affecting their health, therefore the issues associated with frailty appear to be the main area to address for the majority of people.

The follow-up MYCaW® form also asked people to identify what had been most important about the frailty service. By far the most frequent response was the support and understanding that they received. This type of data is often never systematically captured but is incredibly valuable to highlight to staff that their kind and supportive approach is highly valued by the patients. This feedback is testament to the professionalism of staff in the face of very tough operating conditions.

5.3 Limitations of this work

This project was aimed at piloting MYCaW® and understanding how it performs; whether it can identify the appropriate concerns from the frail population and show changes in the severity of the people's concerns and wellbeing.

The amount of time spent implementing MYCaW® was considerable, as it would have been with any new outcome measures. It required processes to be developed, agreed, and tested with a large team of people and was possible due to a great deal of hard work from everyone involved. The staff experience of using MYCaW® was positive and there was a lot of knowledge sharing and learning. There is no doubt that the implementation process was adversely affected by the additional pressures that healthcare staff were dealing with due to the pandemic, especially during the 'winter pressures'.

As previously mentioned in the report, some data analysis should be treated as preliminary findings only due to the n value being low. There were a lot of people where follow-up scores were not obtained but data wasn't available to understand fully what was affecting the capture of follow-up scores. There are several possibly explanations here. Due to the increased risk of being seriously ill, hospitalised or dying from Covid-19, it is likely that some of the participants would have become ill, and may have passed away therefore preventing follow-up scores being collected. There was no hospital admission data, mortality data or data on the number of people infected with Covid-19 to analyse for this dataset. This is a further stage of analysis that could be conducted.

As documented in the introduction, both services were forced to operate in unusual circumstances which affected how often they were able to visit patients and the type of care needed when visiting them. This may have meant that in some cases it was inappropriate to conduct a follow-up MYCaW® form and that more urgent and acute care needed to be provided. This means that the data only represents a proportion of the services, and that the data cannot be used to make firm conclusions at this stage.

The changes in the patients’ concern and wellbeing scores may not be directly attributable to the service provided. This can only be determined with a control group. Patients were given the option to identify other things that may be affecting their health and only a small proportion did so. Generally, they identified other health conditions that were impacting them. To understand the impact of the confounding external factors it is possible to audit people who had a deterioration in score to understand what their MYCaW® concerns were, and if they had stated other issues they were experiencing. That type of analysis was beyond the scope of this study.

6.0 Conclusion

The aim of this pilot project was to implement MYCaW® into the frailty service and then understand if the data collected is useful to the service. This report has shown that MYCaW® is indeed a useful tool to be used in the context of frailty and importantly, staff view it as a useful and acceptable tool to use in consultations. The tool was implemented in services' systems and data was successsfully collected from a fragile cohort during the Covid-19 pandemic. The data shows that despite people experiencing moderate or severe frailty, their designated MYCaW® concerns scores showed statistically significant improvements and a high percentage of people had meaningful levels of score changes. When that data was stratified for Rockwood frailty severity, only people experiencing mild frailty had a statistically significant improvement in their wellbeing – however this is only a preliminary finding. Rockwood scores did not change over time.

A bespoke qualitative coding framework from the frailty setting has been created and this provides a rich picture of the breadth of concerns that are important to frailty patients. The most frequent concerns related to mobility, managing the household and ADLs, physical problems, housing and independence. Importantly this information can be used by healthcare practitioners to improve the personalised nature of the support they provide.

7.0 Recommendations

There are several key recommendations that have come out of this work which are detailed below.

7.1 Ongoing MYCaW® usage

The data and experience of healthcare practitioners has shown that using MYCaW® was viable within consultation times, and felt to be reporting useful data. It is therefore recommended that MYCaW® is continued to be used in the frailty services and potentially implemented in other frailty services.

If more staff are to use MYCaW® it is recommended that they attend some basic training on how to administer it and how to manage situations where they are not sure if an outcome measure should be collected. This training proved popular in this pilot study.

7.2 Understanding why follow-up scores were not always collected

Whilst 310 people filled in baseline MYCaW® forms, follow-up data was only available for 113. For quality improvement purposes it is important to establish the reasons that contribute to this lower follow-up number, to determine if circumstances are beyond the control of the service or not. It is recommended that the following is investigated:

- The number of patients with a baseline MYCaW® questionnaire who were admitted to secondary care before their follow-up
- The number of patients with a baseline MYCaW® questionnaire who passed away before their follow-up
- The number of patients healthcare practitioners felt unable to carry out a follow-up MYCaW® questionnaire with and why

This information can then be interpreted and any tweaks to the operating protocols around MYCaW® can be made. Potentially these data could be collected and added into the spreadsheet of data for ongoing MYCaW® analysis.

7.3 Volume of data collected

As with all pilot studies, the primary aim was to implement, create standard protocols and ascertain acceptability, in this case with MYCaW®. Moving forwards, the trends in the data from this pilot need to be confirmed by collecting more MYCaW® data. Once recommendation 7.2 has been addressed, more information will be known about why follow-up MYCaW®collection was low.

- Taking into account any changes to protocols made, it is ideal to have follow-up scores for 80% of service users to feel more confident that the mean data represents the majority of services users.
- To analyse the data for each service provider, it is recommended that a minimum of 120 patients with baseline and follow-up MYCaW® scores are analysed for each service provider, to enable enough power to be confident in the statistical analysis and the overall trends that are emerging.

7.4 How does the severity of frailty affect wellbeing?

The findings on wellbeing are very interesting - the trend emerging is that improvements in wellbeing were less likely to be reported over time as frailty becomes more severe. This is worth understanding in more detail.

It is recommended that enough MYCaW® data is collected at follow-up to have at least 120 patients in each frailty group – mild, moderate and severe. This will enable confidence in the statistical analysis and will highlight how the degree of improvement in MYCaW® scores and wellbeing may be affected as frailty become more severe.

7.5 Do the patterns of MYCaW® concerns change with the severity of frailty?

We reported a noticeable change in the frequency of MYCaW® concerns when the dataset was stratified according to the Rockwood Clinical Scale. It is recommended that this frequency analysis be repeated when there are at least 200 patients with MYCaW® concerns in each of the mild, moderate and severe categories according to the Rockwood Clinical Scale. This will provide useful information to help services predict the type of concerns they are most likely to encounter depending on the severity of the frailty.

8.0 Appendices

Appendix A: Consent form and MYCaW® tool

One Gloucestershire
Transforming Care, Transforming Communities

NHS
Gloucestershire Health and Care
NHS Foundation Trust

Measure Yourself Concerns and Wellbeing (MYCaW®)

First MYCaW® Date:	☐	**Second MYCaW® Date:**	☐

	Face-to-face	Telephone	Video Consultation
Method of delivery: Please tick relevant box			

	Person	Carer on behalf of person e.g. family	Staff member on behalf of person
Completed by: Please tick relevant box **Please include staff member's name below:**			

IMPORTANT INFORMATION

The South Cotswolds Frailty Service, Complex Care at Home Service and the Clinical Commissioning Group in Gloucestershire are doing some work with the people who have developed the MYCaW® questionnaire, their company is called Meaningful Measures.

Together we are trying to better understand the types of concerns that people have; and understand how we can best work with people to help them address their needs. We are aiming to help Gloucestershire CCG to provide the best frailty service it can.

Throughout the process your identity will be hidden and will not be accessible to the researchers though they will have access to your, age, gender, ethnicity and first three letters of your postcode.

I consent to my anonymised data being shared with Meaningful Measures

☐ Yes

☐ No

If you have any queries about this questionnaire please speak to your matron or wellbeing coordinator. You can contact any member of the team on: 0300 421 1389 or 0300 421 6367.

Thank you for your help. Yours sincerely, Complex Care at Home Team

SAMPLE COPY ONLY – LICENCE FROM MEANINGFUL MEASURES REQUIRED

Measure Yourself Concerns and Wellbeing (MYCaW®)
First form

Today's Date:___________________________

Please tick the relevant boxes below so we can understand more about the data collection:

I am a: (please tick)

☐ Patient completing this on my own

☐ Carer completing this about myself

☐ A carer supporting someone to complete this (e.g. family member)

☐ A professional supporting someone to complete this (e.g. nurse or link worker)

This was completed: (please tick)

☐ During a face-to-face appointment

☐ During a phone/ video consultation

☐ At home, returned by post

☐ Via an online survey

Please write down one or two concerns or problems which you would most like us to help you with.

1.

2.

Please circle a number to show how severe each concern or problem is now:

This should be YOUR opinion, no-one else's!

Concern or problem 1:

☺	0	1	2	3	4	5	6	☹
Not bothering me at all						Bothers me greatly		

Concern or problem 2:

☺	0	1	2	3	4	5	6	☹
Not bothering me at all						Bothers me greatly		

Wellbeing:

How would you rate your general feeling of wellbeing now? (How do you feel in yourself?)

☺	0	1	2	3	4	5	6	☹
As good as it could be						As bad as it could be		

Thank you for completing this form

Measure Yourself Concerns and Wellbeing (MYCaW®)

Follow-up form

Today's Date: ___________________________

Please tick the relevant boxes below so we can understand more about the data collection:

I am a (please tick):

☐ Patient completing this on my own

☐ Carer completing this about myself

☐ A carer supporting someone to complete this (e.g. family member)

☐ A professional supporting someone to complete this (e.g. nurse or link worker)

This was completed: (please tick):

☐ During a face-to-face appointment

☐ During a phone/ video consultation

☐ At home, returned by post

☐ Via an online survey

Look at the concerns that you wrote down last time (please do not change these).
Now circle a number below to show how severe each of those concerns or problems is now:

Concern or problem 1:

☺ 0 1 2 3 4 5 6 ☹

Not bothering me at all — Bothers me greatly

Concern or problem 2:

☺ 0 1 2 3 4 5 6 ☹

Not bothering me at all — Bothers me greatly

Wellbeing:

How would you rate your general feeling of wellbeing now? (How do you feel in yourself?)

☺ 0 1 2 3 4 5 6 ☹

As good as it could be — As bad as it could be

Other things affecting your health

The support that you have received here may not be the only thing affecting your concern or problem. If there is anything else which you think is important, such as changes which you have made yourself, or other things happening in your life, please write it here.

What has been most important for you?

Reflecting on your time with us what were the most important aspects for you?

Thank you for completing this form

Appendix B: Guidance developed by Gloucestershire services in collaboration with Meaningful Measures regarding how to implement the MYCaW® tool with people living with frailty

Guidance for staff working with older or vulnerable people

MYCaW® concerns should be elicited at the appropriate time in the first session with a person. There is no fixed point for this.

- We recommend that you carry out wider holistic needs and general conversation about a person's situation and wellbeing, and then near to the end of a session try to introduce the MYCaW® question on concerns and problems.
- This can serve as a way of prioritising what action needs to be taken. It may take a little discussion to find the priorities.
- You may scribe for a person, please keep their words in the first person when you write down the concerns.

When working with older people, not everyone is willing/capable of providing answers to questionnaires on their own. This could be due to cognitive impairment for instance.

- Please use your professional judgement at this stage as to whether you feel it would be better to fill in the form on someone's behalf. As trained professionals you will know if this is the case.
- You may see the person with their carer present in which case the carer may want to complete MYCaW® on the persons behalf.
- Any proxy responses from carer or staff are still important to collect, but, if possible, it is always preferable to obtain the responses directly from the person themselves.
- It is important to tick the relevant box on the page of the tool to show who has filled in the form.

Sometimes it is not appropriate to collect questionnaire data from a person.

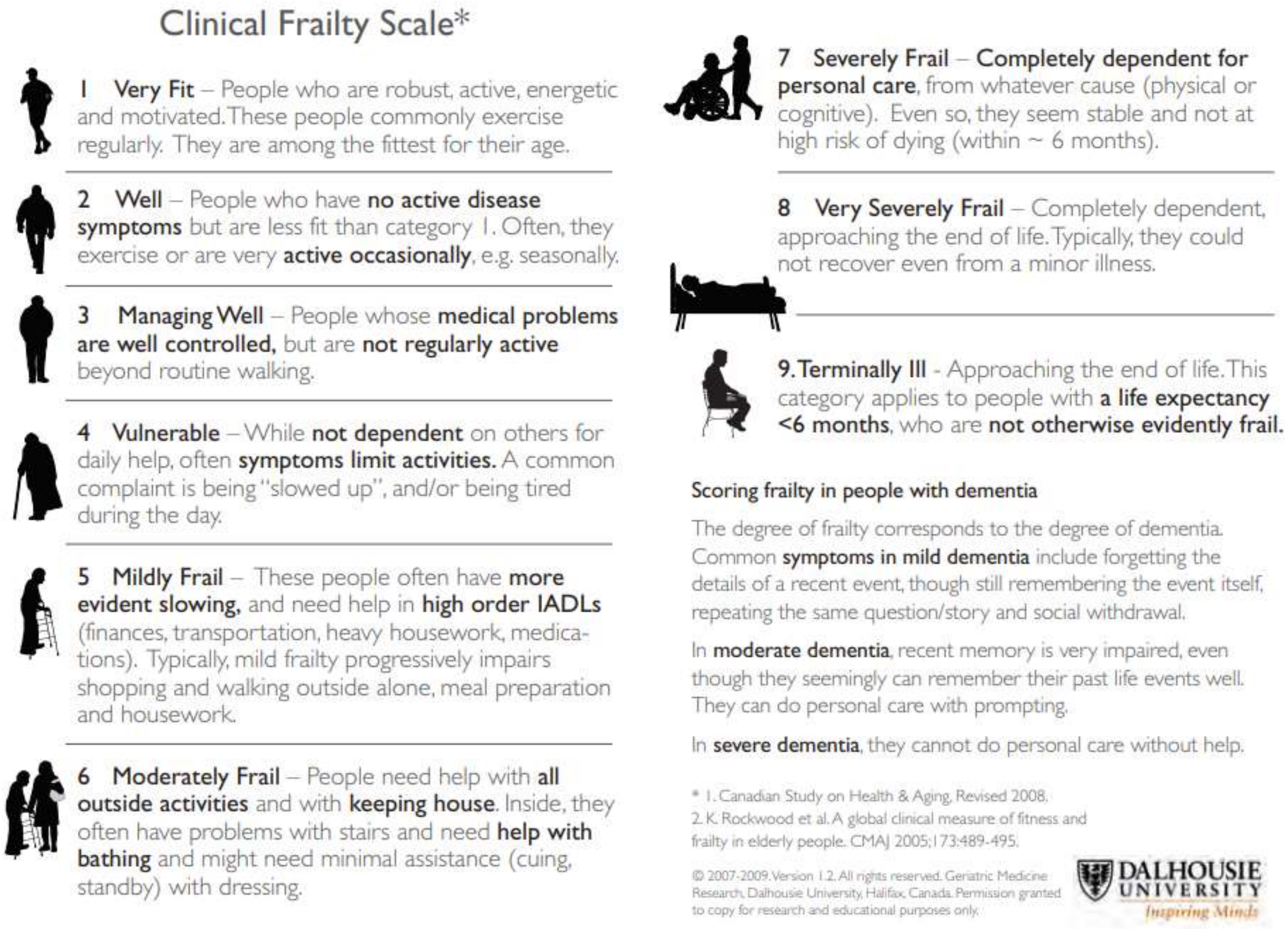
- There are ethical boundaries on collecting data and a person may be too agitated or anxious and by collecting data on a questionnaire this may feel inappropriate to the conversation that is taking place. Whilst MYCaW® is a very 'consultation-friendly' questionnaire, there may still be times when it isn't appropriate.
- A person has the right to refuse to provide answers.
- A person may not be capable of understanding the questions and there may not be another person to complete the questionnaire.
- Meaningful Measures respects your professional judgement in these situations.
- It is good practice to record why MYCaW® was not completed, so it doesn't look as if it was missed out. Please add a note in the concerns box and/ or top sheet if this happens.

Any other questions please contact hello@meaningfulmeasures.co.uk

Appendix C: Rockwood scale

Community services currency guidance: frailty and last year of life NHSE doc states that mild/ moderate and severe frailty on Rockwood are classified as follows:

- **Mildly frail (CFS score of 5 or less)**
- **Moderately frail (CFS score of 6)**
- **Severely frail (CFS score of 7 or more)**



Clinical Frailty Scale*

1 **Very Fit** – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.

2 **Well** – People who have **no active disease symptoms** but are less fit than category 1. Often, they exercise or are very **active occasionally**, e.g. seasonally.

3 **Managing Well** – People whose **medical problems are well controlled,** but are **not regularly active** beyond routine walking.

4 **Vulnerable** – While **not dependent** on others for daily help, often **symptoms limit activities.** A common complaint is being "slowed up", and/or being tired during the day.

5 **Mildly Frail** – These people often have **more evident slowing,** and need help in **high order IADLs** (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.

6 **Moderately Frail** – People need help with **all outside activities** and with **keeping house**. Inside, they often have problems with stairs and need **help with bathing** and might need minimal assistance (cuing, standby) with dressing.

7 **Severely Frail** – **Completely dependent for personal care**, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).

8 **Very Severely Frail** – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.

9. **Terminally Ill** - Approaching the end of life. This category applies to people with **a life expectancy <6 months**, who are **not otherwise evidently frail.**

Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia**, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In **severe dementia**, they cannot do personal care without help.

* 1. Canadian Study on Health & Aging, Revised 2008.
2. K. Rockwood et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005;173:489-495.

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Appendix D: Demographic data

Age brackets	%
45-49	0.9
50-54	0.9
55-59	2.6
60-64	6.1
65-69	0.9
70-74	9.6
75-79	7.9
80-84	18.4
85-89	33.3
90-94	15.8
95-99	3.5
100-104	0

Table 9. % spread of 5-year age bands of n=113 people providing MYCaW® data

Gender	72.8
Female	59.6
Male	40.4

Table 10. % spread of gender for n=113 people providing MYCaW® data

Ethnicity	
White	72.8
non-white	3.5
Not stated	23.7

Table 11. % spread of ethnicity of n=113 people providing MYCaW® data

Postcode	%
OX18	0.9
SN6	0.9
GL1	1.8
GL14	0.9
GL15	0.9
GL17	0.9
GL2	6.1
GL3	6.1
GL4	14.9
GL50	5.3
GL51	11.4
GL52	6.1
GL53	1.8
GL54	3.5
GL7	38.6
GL8	0.0

Table 12. % spread of postcode area of n=113 people providing MYCaW® data

Appendix E: Evolution of MYCaW® coding frameworks, from original integrative oncology framework to new frailty framework

Concerns Supercategory	Integrative Oncology Categories	Frailty Categories
S1 - Psychological and Emotional Concerns	Adapting and coping	-
	Body image concerns	-
	Confidence issues	Confidence issues
	Depression/low mood	Depression/low mood
	Emotional problems	Emotional problems
	Family and relationships	-
	Fear and anxiety	Fear and anxiety
	Psychological issues	-
	Regaining balance and normality	-
	Sleep problems	Sleep problems
	Stress and tension	-
	Support	Support
	The future	The future
	-	Loneliness
	-	Dementia/memory problems/confusion
	-	Lack of motivation
S2 - Physical Concerns	Hot flushes and night sweats	-
	Fertility	-
	Pains/aches	Pain/aches
	Physical problems not related to cancer	Other physical problems/conditions
	Poor energy levels	Poor energy levels/fatigue
	Cancer recurrence	-
	Spreading of cancer	-
	Weight change	Weight change
	-	Breathing problems
	-	Diabetes/pre-diabetes
	-	Continence
	-	Sight/vision
	-	Mobility
	-	Falls
S3 Hospital Cancer Treatment Concerns	Cancer treatment in general	-
	Side effects of chemotherapy	-
	Side effects of hormonal treatment	-
	Side effects of surgery	-
	Side effects of radiotherapy	-
S3 - Healthcare and service provision concerns	-	Care and support information (general)
	-	Healthcare provision and support
	-	Other services
S4 - Concerns about Wellbeing	Exercise/Physical activity	Exercise/Physical activity
	General wellbeing	General wellbeing

	Healing	-
	Information and guidance on	-
	Complementary therapies	-
	Nutrition and diet	Nutrition and diet
	Relaxation	-
	Spiritual wellbeing - meaning and peace	-
	Spiritual wellbeing - faith	-
	-	Getting out
	-	Independence
	-	Social interaction
S5 - Practical Concerns	Finances	Finances
	Work	-
	-	Housing
	-	Managing the household/assistance with daily living
	-	Transport
	-	Other practical concerns
S6- Concerns about a carer or partner/family member		Support of a carer or partner/family member
		Worries about a carer or partner/family member

Other things going on life? Super category (OT)	**Integrative Oncology Categories**	**Frailty Categories**
OT1 Awareness of wellbeing	Taking exercise	Taking exercise (positive)
	Improved nutrition	-
	Improved awareness of own wellbeing	Awareness of own wellbeing (Positive and negative)
	Difficulties in maintaining change	-
OT2 Receiving complementary therapies	Benefit of therapies at the centre	-
	Benefit of therapies outside of the centre	-
OT3 Major life events	Positive change of environment	Positive change of environment
	Negative change of environment	Negative change of environment
	Bereavement	Bereavement
OT4 Social support	Increased social support	Increased social support (positive)
	Family problems	Family (positive)
	General lack of support	-
	-	Partner (positive and negative)
OT5 Work situation	Improved work set-up or financial situation	-
	Work or financial problems	-
OT6	Cancer related and positive	-

Health issues	Cancer related and negative	-
	Non cancer related	-
	-	Positive
	-	Negative
	-	Neutral
	-	Receiving support from health professionals (positive and negative)
OT7 Other	Misc	Misc

What was important?	**Integrative Oncology Categories**	**Frailty Categories**
	Support and understanding received	Support and understanding received
	Individual and group therapies	-
	Access to therapies	Access to services/support
	Confidence in the therapists	Confidence in staff
	Care and kindness	Care and kindness
	Being with other visitors	-
	Relaxation and time for self/ self-development	-
	The environment / atmosphere	-
	Appreciation of the centre and its resources	Appreciation of service and its resources
	Negative feedback	Negative feedback
	Non-specific	Non-specific
	-	Independence
	-	Wellbeing

Appendix F: Staff feedback from using the tool

Staff Feedback questions regarding the use of MYCaW® Staff either using the tool in clinical practice or administrating the tool managing the data processing, store and reporting within their organisation were asked the following questions.

1. Were there any issues with collecting data using MYCaW®? (practical data collection issues, wording, instances it didn’t work)
2. Were there any issues with embedding the MYCaW® data collection in your digital systems? (eg. EMIS/ SystmOne? Or any other systems you use)
3. Were there any issues with creating or using templates for MYCaW® in your digital systems?
4. Were there any issues with creating reports for MYCaW® data to output to Meaningful Measures?
5. What was the overall experience of using the MYCaW® tool in your work? (Does the tool fit your work needs, patient needs?).

9.0 Glossary

- ADL - Activities of Daily Living. Activities of daily living (ADLs or ADL) is a term used in healthcare to refer to people's daily self-care activities. Health professionals often use a person's ability or inability to perform ADLs as a measurement of their functional status.
- EMIS - EMIS Health, formerly known as Egton Medical Information Systems supplies electronic patient record systems and software used in primary care, acute care and community pharmacy in the United Kingdom. EMIS is one of the suppliers approved by the GP Systems of Choice and so funded by the NHS, similar to SystmOne.
- Frailty - a person's mental and physical resilience, or their ability to bounce back and recover from events like illness and injury.
- GHC - Gloucestershire Health and Care NHS Foundation Trust is an NHS foundation trust which provides physical health, mental health and learning disability services throughout Gloucestershire.
- MYCaW® - MYCaW® (Measure Yourself Concerns and Wellbeing) is an individualised outcome measure used for evaluating holistic and person-centred approaches to supporting people. It is a short, validated tool that can be routinely incorporated into a consultation to see where a person most wants support, or used in an organisation to improve workplace wellbeing.
- Rockwood Clinical Frailty Score (CFS) - The Clinical Frailty Scale (CFS), being used by the NHS to help decide which people are most likely to recover, ranks frailty from one to nine.
- SystmOne is one of the computer systems available to GPs, similar to EMIS.
- South Cots Frailty Service - South Cotswolds Frailty Service is an anticipatory care community service embedded in and delivered by the South Cotswolds PCN.

END