


Developing a framework of concerns from people living with frailty, for the Measure Yourself Concerns and Wellbeing (MYCaW) person-centred outcome measure

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ABSTRACT

Introduction Measure Yourself Concerns and Wellbeing is a validated person-centred outcome measure, piloted as a core monitoring tool to understand what matters to people living with frailty in Gloucestershire. This paper describes the acceptability of MYCaW used in this setting, and the development of a framework for analysing personalised concerns from people living with frailty.

Methods MYCaW was implemented in the Complex Care at Home service and South Cotswold Frailty Service from November 2020 onwards. MYCaW was completed at the person's first meeting with a community matron and then 3 months later. Nineteen staff completed an anonymous survey to provide feedback on the acceptability of the tool. A framework of concerns bespoke to people living with frailty was created via iterative rounds of independent coding of 989 concerns from 526 people. The inter-rater reliability of the framework was determined by using the Cronbach alpha test.

Results MYCaW was simple to use and helped health professionals' discussions to be patient focused. A pictorial scale accompanying the Numerical Rating Scale was developed and tested to help people engage with scoring their concerns and well-being more easily. A framework of concerns from people living with frailty was produced with five main supercategories: Mental and Emotional Concerns; Physical Concerns; Healthcare and Service Provision Concerns, Concerns with General Health and Well-being and Practical Concerns. Inter-rater reliability was kappa=0.905.

Conclusions MYCaW was acceptable as a core monitoring tool for people living with frailty and enabled a systematic approach to opening 'What Matters to Me' conversations. The personalised data generated valuable insights into how the frailty services positively impacted the outcomes for people living with frailty. The coding framework demonstrated a wide range of concerns—many linked to inequalities and not identified on existing outcome measures recommended for people living with frailty.

INTRODUCTION

Frailty is defined as a state of increased vulnerability to negative outcomes due to a

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ As rates of frailty increase sharply in the oldest quartile of the population, identifying and supporting the needs of people who are frail is an increasing priority. The aim of this project was to investigate the acceptability of using the Measure Yourself Concerns and Wellbeing (MYCaW) person-centred outcome measure within a frailty service to understand and prioritise what a person most wants support with.

WHAT THIS STUDY ADDS

⇒ MYCaW was found to be simple to use and helped to keep health professionals' discussions with their patient centred on what was important to them. A pictorial scale and framework of concerns from people living with frailty was produced (Concern supercategories were: Mental and Emotional Concerns; Physical Concerns; Healthcare and Service Provision Concerns, Concerns with General Health and Well-being and Practical Concerns).

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ MYCaW can be used as a core monitoring tool for people living with frailty and enables a systematic approach to opening 'What Matters to Me' conversations. This approach supports the evaluation of interventions in evidencing the outcomes achieved with individuals. In a policy environment, MYCaW is a tool that enables a meaningful approach to understanding a person's concerns, supports personalised care planning, co-production and identification of inequalities.

decline in physiology, psychology and cognition in a person.¹ Although identifying frailty in people is at times challenging,² 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, a reduction in physical and social activity, increased risks of falls, disability, institutionalisation



and mortality.^{3–5} As the average age of the UK population continues to increase, identifying and supporting people 65 years and over who live with moderate or severe frailty was made a routine part of the National Health Service (NHS) General Practice contract in 2017/2018. There is debate on how useful the electronic frailty index is, which was recommended for identifying people who are frail,^{6,7} how frailty is conceptualised by medical practitioners⁶ and what outcome measures are suitable to monitor impact of frailty on a person.⁸ Nevertheless, local frailty strategies are being put into action in the English NHS.⁹

The Gloucestershire Integrated Care System (ICS), has developed a number of strategies and transformation programmes which inform personalised proactive models of working with people living with frailty. These include the ICS Frailty Strategy (2022–2027),¹⁰ which focuses on improving resilience and reducing the risk and impact of frailty and the Ageing Well Programme with a key workstream of Proactive Care which identifies people living with frailty as a main cohort. Both of these are underpinned by a One Gloucestershire strategic approach to embedding personalisation in practice.

Measure Yourself Concerns and Wellbeing (MYCaW) was piloted as a core monitoring tool by the Gloucestershire Clinical Commissioning Group, (now Gloucestershire Integrated Care Board) to understand what matters to people living with frailty in Gloucestershire. Initially MYCaW® was implemented in the Complex Care at Home service (CC@H) and the South Cotswold Frailty Service (SCFS). MYCaW is a person-centred outcome measure, which enables a person to designate their concerns, rate the severity of them and their well-being. At follow-up the concerns and well-being are rated once more to enable statistical analysis of score changes to be carried out. Further qualitative follow-up questions ask if there is anything else important going on in a person's life and what has been most important about the service they have received. More details on the development, validation and analysis of MYCaW data can be found in previous publications.^{11–14} MYCaW is now owned and licensed by Meaningful Measures Ltd and has been accredited by the NHS for use in supported self-management.

This paper describes how we have assessed the acceptability of MYCaW for use by a range of healthcare professionals supporting people living with frailty in Gloucestershire. Furthermore, we describe the development of an analysis framework of MYCaW concerns from this sample population of people living with frailty. Using a framework enables different frailty services to compare person-centred data with a standardised format, to understand the range of concerns that people have and develop fully person-centred services to support this population.

METHODS

Implementation of MYCaW®

Throughout the project monthly meetings were held between the clinical teams, management and Meaningful

Measures Ltd. During July to October 2020, three online, 1-hour training sessions on the practical administration of MYCaW were provided by Meaningful Measures Ltd to all staff who would be using the tool. Further guidance was provided to support professionals administering MYCaW in the form of a script on how to explain MYCaW and bring it into a clinical conversation. A robust Data Protection Impact Assessment was carried out with all partners. Business intelligence staff within the service provision teams, in collaboration with Meaningful Measures Ltd, developed local templates on SystemOne and EMIS for recording MYCaW baseline and follow-up data digitally. Further secure procedures for anonymising and transferring data between the NHS and Meaningful Measures Ltd were developed. A consent statement for the collection of MYCaW data was co-produced, informing patients of the purpose of collecting MYCaW data and the ability to opt out.

Recruitment of patients (November 2020 to April 2023)

Between November 2020 and April 2023, participants for this pilot project were recruited via either the CC@H or SCFS service (further description of these services can be found in online supplemental table 1). People were assessed using the Rockwood Clinical Frailty Scale (RCFS),¹⁵ a tool used to aid healthcare professions to assess the level of frailty in adults over the age of 65 years. To be eligible, people had to have an RCFS score of at least mildly frail, that is, 5 or more.¹⁵ Patients were excluded if they were living in a care home (as the service specifically supported people living in their own home), or were under 18 years old. Participation was optional—information about why the MYCaW data was being collected was read to each person to gain their consent or provide an opportunity to opt out.

Data collection (November 2020 to July 2023)

Between November 2020 and July 2023, qualifying RCFS data was collected during the initial assessment of a person. Baseline MYCaW data was collected by operational teams including community matrons during their first or second session with a patient. Follow-up MYCaW data was collected approximately 3 months later, where possible. If a person passed away before follow-up data collection this was noted. If data was collected at a face-to-face consultation, paper forms which a patient could write on were used. Written responses from the paper form were photographed on a community matron's work phone and the data entered into the patient's digital record by an administrator and the photo of data deleted. For consultations via phone/video call, verbatim MYCaW responses were typed into SystemOne or EMIS by the consulting healthcare professional.

Acceptability of MYCaW as a core outcome measure for people who are frail

In September 2021 a short anonymous survey was sent via email, to the staff team within the CC@H and SCFS

Phase 1 (Date November 2020 – September 2021)

546 MYCaW® concerns from 201 people living with frailty.

Independent deductive content analysis by two researchers to develop a pilot framework.

Pilot framework independently tested by third researcher for usability. Discrepancies and ambiguities identified, discussed and resolved.

Draft MYCaW® framework for people living with frailty developed.

Phase 2 (October 2021 – June 2023)

Additional 443 MYCaW® concerns from 319 people living with frailty added to dataset.

Draft MYCaW® framework test with full dataset of 989 concerns from 629 people

Independent deductive content analysis by a third independent AHSN researcher. Discrepancies and ambiguities identified, discussed, and resolved.

Inter-rater reliability score calculated.

Final MYCaW® framework for people living with frailty developed.

Figure 1 Process of analysing MYCaW concerns data to develop the MYCaW Frailty coding framework. MYCaW, Measure Yourself Concerns and Wellbeing. AHSN is Academic Health Science Network, now rebranded to Health Innovation Network.

using MYCaW. This was repeated again in June 2023. The survey aimed to understand if MYCaW was suitable to use in their work environment, was acceptable to use with patients and if there were any scenarios in which MYCaW did not work with patients. Furthermore, staff were asked if there were any practical issues inputting data into SystemOne or EMIS or if they had any other comments about MYCaW. Responses were analysed using content analysis.

Development of the frailty framework of MYCaW concerns

The first framework of MYCaW concerns was developed in 2007¹⁴ and updated in 2015¹² using data from 1108 people living with cancer. Parts of the original cancer framework were therefore not relevant to people living with frailty. Using the MYCaW concerns data from people living with frailty, collected by CC@H and SFCS, in iterative rounds of independent deductive content analysis and coding were carried out—see figure 1.

Initially all relevant coding categories from the original MYCaW coding framework were identified and redundant ones were excluded. While carrying out data analysis, some existing categories were expanded or adapted to accommodate different contextual information. New categories were also developed if an existing category was not available to be adapted and there were at least 10 similar mentions of a concern. A detailed description of what the researchers included in each category was recorded as categories were adapted or developed, to enable category inclusion criteria to be produced. All

Table 1 Demographics of people with frailty who completed Measure Yourself Concerns and Wellbeing concerns

Category	Percentage (%)	
Gender	Female	56
	Male	40
	Not stated	4
Age (years)	40–49	3
	50–59	3
	60–69	7
	70–79	22
	80–89	41
	90–99	24
Ethnicity	Not stated	1
	White	66
	Non-white	6
	Not stated	28

new categories were located within the appropriate supercategory and a final review of whether the supercategory names and descriptions were appropriate was carried out.

To test the usability of the final frailty framework 989 concerns from people living with frailty were independently coded by RB, a researcher from Health Innovation Wessex. Using a ‘naïve’ researcher (defined as no prior involvement in development of the framework or data collection), enabled a completely fresh perspective on the usability of the frailty framework to be gained. Any discrepancies were noted and resolved through discussion between RB, MJP and HES, to produce the final version of the frailty framework. Furthermore, the inter-rater reliability of concerns coding between RB and MJP was calculated to determine the level of coding agreement.

Patient and public involvement

The main body of this research was to determine the acceptability of using the MYCaW outcome measure with patients and determine systematic ways to document a person’s voice. People living with frailty were not directly involved in the design or analysis of this research.

RESULTS

The demographics of the sample population are shown in table 1. The modal participant was 80–89 years old (41% of sample), women (56%) and white (73%), 116/647 (17.9%) had passed away during data collection.

Acceptability of MYCaW as a core outcome measure for people who are frail

Nineteen responses to the anonymous survey sent to staff using MYCaW were obtained from a range of professionals including community matrons, health and wellbeing coordinators, occupational therapists, physiotherapists, service leads and an IT training manager. Due to

anonymous completion, there may have been a small amount of duplication of staff responses from 2021 to 2023. 16/19 professionals stated that there were no issues using MYCaW, that it was a positive experience, as the tool was simple to use, fitted their work and patient needs and helped to keep their discussion with their patient focused.

It's very simple to use. (Community Matron)

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. (Community Matron)

Other professionals noted how MYCaW enabled them to understand what is most important to their patient and gather feedback from them.

Really good conversation starter and enables the service to gather rich data and feedback on patient and service outcomes. (Service Lead)

Keeps focus for the patient – professional relationship – working together for what is most important to the patient. (Health and Well-being Coordinator)

It captures a snapshot of what is or is not working for the patient. (Occupational Therapist)

Three people highlighted practical implementation issues around how the MYCaW data is inputted or uploaded onto the digital system, but not with the tool itself.

Improving accessibility of MYCaW

Collecting data from people with dementia was noted by the community matrons to be challenging at times. A guidance document on how to manage this process was co-produced by Meaningful Measures Ltd, the commissioner and the community matrons, to ensure everyone was following an agreed procedure. The guidance highlighted when to move to using a proxy person to complete MYCaW (eg, a carer), or when collecting any form of outcome data was not appropriate. A pictorial scale was also developed to accompany the numerical MYCaW scale to aid patients when rating their concerns and well-being (see figure 2). This development built on a similar pictorial scale piloted for a sister tool Measure Yourself Medical Outcomes Profile in 2004.¹⁶ The community matrons trialled the pictorial scale and found that it improved the ability of people to rate their concerns and well-being.



Figure 2 Pictorial scale used to support the rating of concerns and levels of well-being, using Measure Yourself Concerns and Wellbeing tool.

Development of the MYCaW concerns framework for people living with frailty

Having a coding framework provides a standardised approach to analysing and comparing the frequency of individualised concerns across different services or geographical locations.

After two rounds of robust independent analysis of 989 concerns from 629 people, and testing of the framework on additional independent researchers (see figure 1), a final version of the framework of MYCaW concerns from people with frailty was produced (see table 2). The framework contained 5 main supercategories split into 36 specific categories. A detailed version of the framework contains detailed inclusion criteria for each category. This can be accessed via Meaningful Measures Ltd.

The evolution of the framework can be reviewed in online supplemental table 1. Eighteen original categories were removed as they were not relevant to this sample population. This included removing a whole theme—Hospital Cancer Treatment Concerns. Nine categories were kept the same, where the concerns were common across both groups of people. A further nine categories from the original framework were adapted or amalgamated to cater for different contextual information. Twenty-two new categories were added across all the supercategories, many categories being more specific to issues experienced with frailty, such as mobility and falls, medication issues, continence, healthcare and social care provision, independence, digital concerns, managing the household and daily living.

After the final round of developing the frailty framework, the coding by RB and MJP were compared and analysed for inter-rater reliability. A kappa score of 0.905 was achieved denoting a very high level of agreement in coding between the researchers.

DISCUSSION

Identifying the needs of people who are deemed frail

While our understanding of frailty has progressed, there remains disagreement on the conceptualisation of frailty among healthcare practitioners and how frailty is identified.^{2 6 7 17} Moreover, as highlighted by Conroy and van Oppen,⁸ many outcomes that matter to older people with frailty are not routinely collected by the NHS. Despite these issues, people with complex conditions need personalised support. To provide appropriate support, a person's priorities and needs must first be identified. MYCaW was developed in 2006¹⁸ as a simple, non-hierarchical approach to hearing what was concerning a person the most and how this was affecting their well-being. MYCaW concerns were first developed into a systematic framework in 2007,¹⁴ based on a sample population of people who were living with cancer and a further framework developed based on carer's concerns.¹¹ The use of MYCaW has spread to many different sample populations, particularly in the NHS, as it is now accredited for use with supported self-management approaches.

Table 2 Framework of Measure Yourself Concerns and Wellbeing concerns from people who are mild-to-severely frail

Theme	Code	Category
T1-Mental and Emotional Concerns Includes concerns relating to psychological and emotional issues. It excludes physical concerns.	T1a	Confidence issues
	T1b	Depression or low mood
	T1c	Mental health concerns
	T1d	Anxiety and worries
	T1e	Sleep problems
	T1f	Family and relationships
	T1g	The future
	T1h	Loneliness, isolation and bereavement
	T1i	Dementia/memory problems/confusion
	T1j	Lack of motivation
	T2-Physical Concerns Includes concerns relating to physical aspects of a person.	T2a
T2b		Pains or aches
T2c		Other physical problems or concerns
T2d		Energy levels or fatigue
T2e		Weight changes
T2f		Continence
T2g		Sight and hearing
T2h		Mobility
T2i		Falls or balance issues
T2j		Breathing problems
T3-Healthcare and Service Provision Concerns Includes concerns relating to healthcare, support and external services.		T3a
	T3b	Healthcare or social care provision
	T3c	Physiotherapy and strength
	T3d	Medication
T4-Concerns about General Health and Well-being Includes concerns about wider issues around living well and regaining or maintaining one's well-being.	T4a	Physical activity or exercise
	T4b	General health and well-being
	T4c	Nutrition and diet
	T4d	Getting out
	T4e	Independence
	T4f	Social interaction
T5-Practical Concerns Includes data about non-health-related concerns.	T5a	Finances
	T5b	Housing
	T5c	Managing the household/assistance with daily activities of living
	T5d	Transport
	T5e	Other practical concerns
	T5f	Digital
T6-Concerns that cannot be coded	T6	Use this code when: <ul style="list-style-type: none"> ▶ Concerns not completed due to issues with dementia, cognition or a person's loss of ability to generate a concern for themselves. ▶ 'Declined' or 'none' written down. ▶ Concerns without enough context to code. ▶ Items written as update not as a concern.

MYCaW use in a frail population

This paper reports the first set of MYCaW concerns and development of a framework using data from people living with frailty as a dedicated sample population. Because MYCaW allows a person to nominate their primary concerns, this allows them to talk about issues that are relevant to them. This might be a medical condition or situation they are being supported for, or other pressing concerns associated with social determinants (eg, housing, working, finances, digital issues). Whatever the concerns may be, if these are their most pressing concerns then they will likely be detrimentally affecting their well-being. As such these concerns should be supported as a priority.

The MYCaW frailty framework identified 36 concern categories split into 5 themes: Mental and Emotional Concerns; Physical Concerns; Healthcare and Service Provision Concerns; Concerns about General Health and Well-being; Practical Concerns. While comparing this framework of concerns to other similar outcome measures recommended in this population, it was noted how some aspects affecting a person have not been reported yet. For example, while the Long-Term Conditions questionnaire items broadly picked up most of the concerns frail people identified, concerns relating to finances, transport and digital are missing. Furthermore, these are all health inequalities that need support in this population but cannot be if they are not first identified. A review by Van Oppen *et al*¹⁹ suggest four potential patient-reported outcome measures (COOP/Wonca charts, EuroQoL, McGill QoL expanded and palliative care outcome scale), that could be used with frail older people in an emergency setting. None of these recommended measures had items that were representative of the breadth of outcomes that were important to people, when compared with this MYCaW frailty framework. To differing degrees, items associated with practical issues and health inequities with digital, transport, housing and financial concerns were the most often missing from these pre-itemised outcome measures. In a policy environment where addressing what matters to a person^{8 20–22} and decreasing the impact of health inequities are priorities at a local,¹⁰ national^{21 23 24} and global level,²² there is an urgent need for outcome measures to collect this type of personalised data.

Acceptability and accessibility of MYCaW

Feedback from the anonymous survey to practitioners using MYCaW with people living with frailty highlighted how useful MYCaW was in opening up conversations, understanding what was important to a person and providing rich, relevant personalised data. The tool enables a systematic approach to opening 'What Matters to Me' conversations and provides valuable insights into the extent to which services positively impact the outcomes for individuals and more broadly the cohorts of people they are working with. This evidence is very helpful in establishing the value and benefits of services. This feedback is similar to the view of Conroy and van

Oppen,⁸ who also recognised the value of shared decision-making and asking what matters to the patient. Allowing people to designate whatever concerns are at the front of their mind, fits with the WHO strategy of meaningful engagement.²² This strategy, among other things, calls for individuals with lived experience of chronic conditions to have bi-directional engagement in their conversations with health professionals, and a redistribution of power to enable equal decision-making processes to occur.

It has been noted in previous research^{25 26} that collecting outcome measures data from some people with dementia often fails to mirror meaningful outcomes for people with dementia. It is noticeable that the outcomes mentioned that are often missing for people living with frailty⁸ or dementia^{25 26} are captured using MYCaW. This makes the MYCaW tool a meaningful approach to understanding a person's concerns, thus supporting the awareness, knowledge and understanding of frailty and supporting personalised care planning and co-production.

To increase the accessibility of MYCaW, particularly for patients who found it harder to rate their concerns and well-being using a score, a pictorial scale was developed to accompany the Numerical Rating Scales. Pictorial scales are widely used as alternatives or adjuncts to written items on outcome measures (eg,^{27 28}). After piloting by the community nurses with patients, the addition of the pictorial scale was found to improve the accessibility of MYCaW and people's ability to rate their concerns and well-being.

Approximately 30% of patients were receiving specialist support from Dementia Matrons as well as specialist support due to living with frailty. Community matrons noted that some patients living with frailty and diagnosed dementia felt they had no concerns, despite their carer or the frailty matron recognising that they needed support. A team decision was taken, therefore, to only attempt to collect MYCaW data where it was deemed that the patient had capacity to articulate their concerns. On a few occasions a loved one or carer stated what they thought the concern was, acting as a proxy. There is no way of knowing how accurate this was for the patient. This situation is discussed further by Burks *et al*²⁹ who seeks to understand what influences the proxy person when completing outcome measures and how this may or may not be reflective of the experience of the person living with dementia. There is therefore a category on the frailty coding framework to identify which people were unable to generate concerns.

Limitations

There are several limitations in this project. While nearly 1000 concerns were analysed they were from one geographical area and from limited numbers of people of non-white ethnicities. Limited ethnicity and geography may therefore mean that there are more concerns to be identified and more framework development needed. The authors are open to further collaboration. Processing the data collected using a paper version of MYCaW to

digital format or using the template in SystemOne was identified by staff as difficult at times, however this was a localised practical issue. Finally, the pictorial scale was developed from suggestions by community matrons how it may make it easier to use MYCaW with a proportion of their patients. Further validation testing of this pictorial scale is, therefore, now recommended.³⁰

Conclusion

This paper demonstrated that MYCaW was successfully piloted as a core monitoring tool for use with people living with frailty by Gloucestershire Clinical Commissioning group (now Gloucestershire Integrated Care Board). Clinical and operational staff found the MYCaW tool was simple to use, fitted their work and patient's needs and helped to keep their discussion with their patient focused. Increased accessibility to MYCaW was created by developing and testing an accompanying pictorial scale. From a commissioning perspective MYCaW has enabled a systematic approach to opening 'What Matters to Me' conversations and generated valuable insights into the extent to which services positively impact the outcomes for individuals and more broadly the cohorts of people they are working with. A new coding framework for MYCaW concerns relating to people living with frailty has been produced to support the standardisation of reporting personalised data. This framework demonstrates the wide range of concerns that most bother people, many of which are linked to inequalities and not routinely collected by the NHS or identified on existing outcome measures recommended for people living with frailty. In a policy environment where addressing what matters to a person and decreasing the impact of health inequities are priorities at a local, national and global level, MYCaW is a tool that enables a meaningful approach to understanding a person's concerns, supports personalised care planning, co-production and identification of inequalities.

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