

Frailty Coding Framework for the MYCaW[®] questionnaire

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

February 2022

Dr Helen Seers, Dr Nicole Collaço and Dr Marie Polley



Meaningful
Measures



Introduction

This person-centred frailty framework has been derived from MYCaW® data collected from two frailty services in Gloucestershire. The data is based on 546 concerns in total identified by 310 people (257 people from Complex Care at Home Service (CC@H), and 53 people from South Cotswolds Frailty Service (SCFS)).

Content analysis is used to categorise concerns and follow up data on people's experiences of the service and other important things going on in their lives. This framework is based on the original work carried out by Dr Polley and Dr Seers and is bespoke to the frailty context.

Whilst there were clear trends in the data, there may be more categories identified if MYCaW® was administered to other cohorts of people in different frailty services or if more data collection is carried out in the current services. Therefore, this frailty framework should be viewed as version one and open to minor revision in due course.

The document first sets out supercategories (themes) and categories of concerns identified followed by the definitions of how information was added to each category (for transparency). This enables this framework to be used by other people to analyse data using the same protocol and therefore enable comparison on individualised concerns across different services or different time points.

The next part of the document uses the same approach to identify any other things going on in people's lives that they feel are affecting their health. From previous research we know that particularly difficult or negative things that are happening concurrently reduce the improvement in wellbeing and in concerns, therefore this provides an approach to identify relevant non-service-related issues.

The document then identifies key categories that people identify as important about the service they received.

Finally, the document has the history of the evolution of the coding framework, contrasting the original iteration from integrative oncology data with the frailty data.

Qualitative Analysis Guidelines for MYCaW

Super categories and categories of concerns derived from the MYCaW question asking: *“Please write down one or two concerns or problems which you would most like us to help you with.”*

Supercategory	Categories
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
S5 - Practical Concerns	Finances
	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

Definitions

S1 - Psychological and Emotional Concerns

This category includes concerns relating to psychological and emotional issues. It excludes physical concerns.

Confidence issues

Include direct references to confidence or self-confidence. May not specify in relation to what, or could be related to confidence in the future, walking, and ability to carry out an activity. May also include concerns about lack of confidence.

Depression/low mood

Anything with direct reference to feeling depressed or having low mood.

Emotional problems

Include anything with a direct reference to emotion. This category relates to the need for emotional support, worries in general or references to general mental health issues.

Fear and anxiety

Include anything with direct reference to being fearful, anxious or scared, e.g., fear and anxiety around waiting for the results of medical investigations.

Sleep problems

Any reference to insomnia or poor sleep.

Support

Include anything with a direct reference to feeling unsupported or needing support of some kind. Reference to emotional support goes in section S1e. Reference to support in relation to health professionals goes in section S3b.

The future

Include direct references about the future.

Loneliness

Any reference to feeling lonely or isolated.

Dementia/memory problems/confusion

Any reference to dementia, experiencing memory problems (may be referred to as the 'muddles'), or confusion.

Lack of motivation

Include reference to feeling unmotivated, lack of motivation, putting things off, not feeling bothered to do things.

S2 - Physical Concerns

This category includes concerns about aspects of physical concerns.

Diabetes/pre-diabetes

Any reference to diabetes, pre-diabetes, or blood sugar levels.

Pain/aches

Must refer directly to expressing feelings of pain, discomfort, or aches, anywhere in the body, or to general muscular aches and pains and pain management.

Other physical problems/conditions

Any reference to other conditions/comorbidities. If the reference is directly about diabetes or prediabetes, add to S2a. May also refer to the individual's understanding of their own condition.

Poor energy levels/fatigue

Different to poor sleep as one can sleep well and still have no energy. Include concerns with direct reference to energy levels, fatigue or tiredness. May also include reference to desire to feel more energetic.

Weight changes

Include any references to wanting to, gaining or losing weight, or experiencing difficulties with weight gain/ loss. May also refer to difficulties eating or being concerned about their physical weight, desire to lose weight, and/or changes to appetite.

Continence

Include any reference to bladder and bowel issues or constipation.

Sight/vision

Include any reference to sight or vision, i.e., deterioration of sight/vision, concerns or problems with their sight/vision.

Mobility

Include any direct reference to mobility, or reference to inability to physically move around, or desire to be more mobile.

Falls

Include direct reference to falls or falling, or reference to being scared of falling, or wanting to feel safe from falling.

Breathing problems

Any reference to difficulties with breathing, shortness of breath.

S3 - Healthcare and service provision concerns

This category includes concerns that are in relation to health care and support and external services.

Care and support information (general)

Includes any reference to the need for more information (may be in relation to staying at home), someone to ask for advice/support/guidance (may not specify what type of support/guidance), availability of specific type of support e.g., respite care.

Healthcare provision and support

May include advice from healthcare professionals on medication, medical observations, lack of support, communication between health providers, desire for support. Reference to physiotherapy support goes in section S4a.

Other services

May include reference to services such as dental services, dementia services, access to these services, “meals on wheels.”

S4 - Concerns about Wellbeing

This category includes concerns about wider issues around living well and regaining or maintaining one’s wellbeing.

Exercise/Physical activity

References around starting to exercise or be more physically active, returning to exercise, doing more exercise. May also include any negative comments about not being able to do exercise at the moment or not knowing what exercise to do that is safe for the persons’ circumstances. Also refers to building strength, keeping active, motivation to exercise, the need for physiotherapy support.

General wellbeing

Include references to improving or maintaining general health and wellbeing (e.g. through stopping smoking), preventing hospital admissions, or generally taking more time for self. Also refers to concerns about general wellbeing or concerns about scan/medical results/investigations. If the concerns about medical procedures or results states a person is fearful or anxious about them, then add this concern to S1d

Nutrition and diet

Include any references to concerns pertaining to nutrition or diet, diet/food intake or advice required or getting advice about food intake.

Getting out

Include any reference to getting out of the house or getting outside safely or going out more or desiring to get out.

Independence

Include any reference to the individual’s specific desire to do an activity themselves (e.g., undo jars and bottles themselves). May also include direct reference to the word *independence* (e.g., to be independent at home) or reference to coping with loss of independence.

Social interaction

Include any reference to being part of social groups, wanting to interact/talk with others, befriending or hobbies.

S5 - Practical Concerns

This category includes data pertaining to non health related concerns.

Finances

Include any concerns about a financial situation, this may include benefits, tax, money income.

Housing

Include reference to adaptations to house – e.g., fixing lights or furniture. May also include property issues (selling property/buying property, land issues), moving to a home, having to leave home, desire to remain at home.

Managing the household/assistance with daily living

Include references to the need for help with cooking, administration, paying bills, cleaning, bathing, digital access, using computer, getting dressed, assistance with moving/getting out of bed, access to cleaner.

Transport

Include reference to being able to get around through transport e.g., taxis, car, assistance using mobility scooter or getting back into driving.

Other practical concerns

Include reference to other practical concerns beyond managing the household/daily living such as arranging a funeral, wheelchair access to shops, access to medication, attending appointments.

S6- Concerns about a carer or partner/family member

This category includes people's concerns about a carer or partner/family member.

Support of a carer or partner/family member

Include reference to difficulties in providing support to partner/carer/family member or the need for support in helping to provide care to carer or partner/family member (as the carer or vice versa). May also include reference to not burdening others or not asking for help. May include reference to their life with their partner (e.g., desire to sleep in same bed as partner, having a decent life with their partner), support with partners' mental health.

Worries about a carer or partner/family member

Include reference to wanting to feel less worried about carer or partner/family member. May include worries about how carer or partner/family member would cope if they were not alive, partners emotional wellbeing, worries about impact of health on family.

States no concerns

Some people are unable to state any concerns. Some people declare they have no worries at all, this may be to do with dementia or cognitive decline.

Misc/Not applicable

Data which is incomplete or if the person who filled out the form state 'not applicable.'

Other Things Affecting Your Health (on follow up form)

This section categorises the answers to question 2 on the follow-up MYCaW form. This question states: *“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”*. The supercategories (OT1-OT6), can be used to identify the overall themes of the data. The table provides an overview and is then followed by detailed instructions for breaking the supercategories down.

The comments generally fall into positive or negative categories hence ‘(positive)’ or ‘(negative)’ in the brackets after the subcategory name (below). If you are unable to tell if it is a positive or negative comment then just use the supercategory number i.e., for the social impact supercategory - if it is difficult to know for some people if the situation is positive or negative, code it as OT3.

Table 2. Overview of categories from the data regarding ‘Other things affecting your health’, stated on the follow-up MYCAW form.

Supercategory (OT)	Categories
OT1 Awareness of wellbeing	Taking exercise (positive)
	Awareness of own wellbeing (Positive and negative)
OT3 Major life events	Positive change of environment
	Negative change of environment
	Bereavement
OT4 Social support	Increased social support (positive)
	Family (positive)
	Partner (positive and negative)
OT6 Health issues	Negative
	Positive
	Neutral
	Receiving support from health professionals (positive and negative)
OT7 Other	

Definitions

OT1 Awareness of Wellbeing

This category includes responses about changes made by individuals to their lifestyle, or about the person's feelings and wellbeing in general.

Taking exercise or physical activity (positive)

Any reference to starting or increasing the amount, intensity, or duration of any type of exercise regimen or physical activity.

Awareness of own wellbeing (negative)

Include data that pertains to their physical or emotional wellbeing- refers to feelings of guilt (e.g. feelings of being a hindrance to others), anxiety, worry.

Awareness of own wellbeing (positive)

Enjoying life, confidence due to use of mobility aids, better routine etc.

OT3 Major Life Events

This category refers to major events that occur that do not fit into the other categories.

Negative change of environment

Any references to a stressful change in the environment which is also viewed negatively. May include impact of COVID-19, being rehomed etc.

Bereavement (negative)

The loss of a close member of family or a close friend.

OT4 Social Support

This category contains any references to social support a person is receiving, this can be from friends, family, partners or within social groups.

Increased social support (positive)

Increased support from family / friends/ neighbours.

Family (positive)

Any general comments in relation to family members, such as spending time with family or getting away with the family. Reference specifically to *support* from family members goes in OT4a.

Partner (positive and negative)

Any comments about concerns/worries for partner, stressed about supporting a partner or improvements in relationship, e.g., working together.

OT6 Health Issues

This category relates to any health issues that are continuing and are either positive or negative or neutral

Negative

Any comments relating to specific physical conditions, pain, aches, discomfort. May also include anxiety, fear, worry at length of recovery time etc. running short of inhalers, decline in health, mobility.

Positive

Any positives relating to the person's health such as improved wellbeing, control over condition, putting strategies in place to self-manage.

Neutral

These are health problems that have been identified, but with no reference to whether they are having a positive or negative effect.

Receiving support from Healthcare Professional (split into positive and negative)

Any comments related to support received from health professionals in relation to their health problems. May also include reference to the need for further support.

OT7 Others

This captures the data that doesn't always appear to be directly related to the question asked and so does not fit into the categories above, such as - difficulties getting appointments, lack of routine, addiction, not able to access furniture.

Important Aspects question on follow-up form

The final follow-up question asks: *'Reflecting on your time with us what were the most important aspects for you?'*

1. Support and understanding received

Include any responses that refers to feeling supported, feeling listened to, receiving support through a service or individual, on any level (emotional, spiritual, psychological, physical). May include reference to continuity of care, being encouraged and motivated. Also includes support from someone to talk to, exercise, nutrition/diet, financial, practical, psychological and family support. Support could be from medical professionals, therapists, service or service staff.

2. Access to therapies/services/support

Include data referring to being able to access therapies/services or support. May also include reference to financial support or practical support. For references about support and understanding received, please refer to 'Support and understanding received,' 1.

3. Confidence in the therapists

This section covered the comments about the experience, trust and professionalism of the therapist(s).

4. Care and kindness

Include any comments that pertain to the care or the kindness that was experienced by the visitor/patient - either by a therapist specifically or the staff at the centre/service. Do not include anything that talks about experience or professionalism of the staff - that is for 'Confidence in the therapists' section 4, above.

5. Independence

Include any comments that refer to getting more mobile, increasing mobility, getting by themselves, confidence to do things, confidence in supporting person.

6. Wellbeing

Include any comments that refers to return to health, awareness about themselves (i.e., not as frail as other people), to be pain free, improved quality of life, improved health problems, improving wellbeing (i.e. through exercise and physical activity).

7. Appreciation of the service and its resources

This section covers many aspects of the service such as staff or the resources staff have provided. Often the comments that fit in this section are general in nature and so can't be allocated elsewhere.

8. Negative feedback

To include any data that has a negative basis to it. It may or may not be in reference to a service but could be about their life in general, e.g. struggles with cost of living.

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 Health issues	Cancer related and positive	-
	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