

Supplementary file 3: Preparatory stage

This supplementary file details the three parts of the preparatory stage (1) practitioner consultation (2) Patient and Public Involvement project and (3) national service user survey.

1. PRACTITIONER CONSULTATION

Aim

To gain insight into the concerns and requirements of Healthcare Professionals (HCPs) around advice on risk when talking about Physical Activity (PA) to people living with long term conditions (LTC).

Methods

We distributed an online survey using the commercial Survey Monkey software[1] to two national primary care networks in the UK and the Moving Medicine ambassador network between October-November 2019. The Moving Medicine ambassador network is a network of multidisciplinary HCPs who have expressed an interest in the role of physical activity in the management of long-term conditions. The survey contained six open questions with free-text responses. Two questions collected data about respondent job role and place of work, and four around the perception and experience of risk when discussing physical activity with patients. The survey was tested with two HCPs not involved in the project prior to distribution. Responses were analysed through thematic analysis.

Results

57 responses were received (Doctor 42%, Physiotherapist 33%, Nurse 9%, other 16%). 53% worked in primary care, 28% in secondary care and 19% in other care settings. Responders were asked to select more than one answer for questions 3-6. Leading themes that emerged from the consultation are presented in table 1. Full results are presented in table 2 with subgroup analyses in tables 3 and 4.

Table 1. Summary of leading themes

| Question | Theme 1 | Theme 2 | Theme 3 |
|--|---|--|--|
| 1 What risks are you concerned about when recommending physical activity to patients | Exacerbation of symptoms, causing complications | Demotivating or 'putting off' the patient | Appropriate recommendation of physical activity, tailored to the individual |
| 2 Have you encountered any specific clinical issues or symptoms, related to physical activity, in your patients with long term conditions? | Psychological motivation, patient willingness to change | Worsening of symptoms | Patient concerns regarding worsening of another pre-existing condition |
| 3 What have your patients with long term conditions asked you about their risks of physical activity? | Concerns about risk of worsening of current symptoms | Concerns regarding perceived barriers due to | General safety and development of new symptoms/ events eg pain/myocardial infarction |

| | | | | |
|---|---|---|---|--|
| | | | other symptoms | |
| 4 | What information/ resources/ other would help you to manage risk in clinical practice, when recommending physical activity to people with long term conditions? | Advice regarding specific long-term conditions and safe prescription of physical activity | General advice to give patients about the benefits of physical activity | Leaflets/Posters/Online Resource/Mobile App for patients |

Table 2. All results from practitioner survey

| Question | Theme | Rank | Number of comments |
|---|---|------|--------------------|
| 1. What risks are you concerned about when recommending physical activity to patients? | Exacerbation of symptoms, causing complications | 1 | 29 |
| | Demotivating or 'putting off' the patient | 2 | 9 |
| | No concerns about risk | 3 | 7 |
| | Appropriate recommendation of physical activity, tailored to the individual | 4 | 6 |
| | Adequate support for the clinician recommending physical activity | 5 | 4 |
| | Patients own ability to be physically active | 6 | 2 |
| | Other ^a | 7 | 1 |
| 2. Have you encountered any specific clinical issues or symptoms, related to physical activity, in your patients with long-term conditions? | No issues | 1 | 17 |
| | Psychological motivation, patient willingness to change | 2 | 15 |
| | Worsening of symptoms | 3 | 12 |
| | Patient concerns regarding worsening of another pre-existing condition | 4 | 7 |
| | Other ^b | 5 | 7 |
| | Fatigue | 6 | 3 |
| | Physical activity advice from non-clinical practitioners | 7 | 2 |
| 3. Have you encountered any specific clinical issues or symptoms, related to physical activity, in your | No issues | 1 | 17 |
| | Psychological motivation, patient willingness to change | 2 | 15 |
| | Worsening of symptoms | 3 | 12 |

| | | | |
|--|---|---|----|
| patients with long-term conditions? | Patient concerns regarding worsening of another pre-existing condition | 4 | 7 |
| | Other ^c | 5 | 7 |
| | Fatigue | 6 | 3 |
| | Physical activity advice from non-clinical practitioners | 7 | 2 |
| 4. What have your patients with long-term conditions asked you about their risks of physical activity? | Concerns about risk of worsening of current symptoms | 1 | 21 |
| | No questions from patients | 2 | 17 |
| | Concerns regarding perceived barriers due to other symptoms | 3 | 10 |
| | General safety of physical activity | 4 | 8 |
| | Development of new symptoms or risks ³ | 5 | 4 |
| | Other ^d | 6 | 2 |
| 5. What information/resources/other would help you to manage risk in clinical practice, when recommending physical activity to people with long-term conditions? | Advice regarding specific long-term conditions and safe prescription of physical activity | 1 | 15 |
| | General advice to give patients about the benefits of physical activity | 2 | 10 |
| | Leaflets/Posters/Online Resource/Mobile App for patients | 3 | 10 |
| | When to refer to a physical activity specialist | 4 | 5 |
| | Specific guidelines or algorithms for recommendation of physical activity | 5 | 4 |
| | Not required | 6 | 6 |
| | Other ^e | 7 | 6 |

^a“fully understanding their individual barriers to exercise”

^b“minor injury”; “screening tools used to access physical activity”; “people requiring support to get changed, eg for swimming – volunteers don’t tend to want to support in this area and cost of carers makes a swimming session prohibitively expensive”; “exercise progression and the ability to access further information”; “improvement in physical fitness that translates into better function, or prolonged function in the face of decline; build friendships, confidence, sleep better etc”; “falls off bikes on roads – fractures clavicle, concussion”; “access to facilities, cost or transport problems”

^cWhen stated – “will I have a heart attack”; “death, MI”; “heart attack”; “falls, joint pain”

^d“can’t motivate themselves to do any PA”; “do the risks of being physically active outweigh the risk of staying as I am?”

^e“I think it would be really useful to understand how to manage symptoms rather than being disease specific. We tend to work in chronic diseases whereas what the patient worries about is the symptoms of the disease, this can be tricky with multi morbidity”; “supervised structured classes with time to make friendships”; “some of my SU’s can’t read, struggle to understand written messages”; “support from local ambassadors and motivators”; “history taking”; “some generic disclaimer type documents”

Subgroup Analyses

Table 3. Subgroup analysis of concerns around worsening of symptoms

| Specific symptom of concern | Number of concerns |
|---------------------------------|--------------------|
| Respiratory | 6 |
| Musculoskeletal/ joint pain | 5 |
| Cardiac ^a | 2 |
| Medication related ^b | 2 |
| Dizziness | 2 |
| Blood glucose control | 1 |
| Falls | 1 |
| Psychological issues | 1 |
| Not specified | 1 |

^a When specified – hypertension; hypotension; angina

^b Considerations with antipsychotic medication prescription; fluctuations of heart rate on chemotherapy

Table 4. Subgroup analysis of patient concerns regarding worsening of another pre-existing condition

| Condition of concern | Number of concerns |
|-----------------------------|--------------------|
| Musculoskeletal/ joint pain | 5 |
| Blood glucose control | 1 |
| Not specified | 1 |

Conclusion

This survey corroborates published data showing the HCPs feel they lack knowledge and skills to discuss PA with patients with LTCs. HCPs expressed a significant level of concern about discussing PA with people with LTC. Fear of aggravating symptoms was a common concern. *Primum, non nocere* (first, do no harm) is an important driver of medical practice and fear of conflicting with this was commonly expressed. Further to this HCPs felt that they lacked skills to discuss PA in a constructive way with patients and were concerned that they might demotivate patients further. HCPs highlighted the need for specific resources to help them discuss risk with patients.

2. PATIENT AND PUBLIC INVOLVEMENT

This Patient and Public involvement (PPI) project was undertaken in 2016.[2] Results and insight closely aligned with the objectives of this project and were therefore used to inform the development of this consensus statement.

Aim

To explore service users' views on how the National Health Service (NHS) could better support their needs.

Methods

The PPI team recruited forty participants living with multiple LTC's through hospital-based patient support networks across a range of conditions in the UK. Patients were interviewed either individually or in groups (patient preference) by semi-structured interviews. Interviews were recorded and transcribed and thematic analysis of interview transcripts was carried out.

Results

The participants' age range was 60-92, and the mean age was 74 (SD 7.4). There were four ethnic groups represented. 55% of the participants were female, and 45% were male. The mean number of co-morbidities was 2.85(SD 2.9). The analysis identified that although participants overwhelmingly stated they wanted to become more active, fear of exacerbating the symptoms of health conditions was a major barrier in keeping with published studies examining barriers to PA in multimorbid groups.[3–5] Symptoms of concern included breathlessness, fatigue, muscle weakness and anxiety about falling or 'getting stuck'.

'it is a bit like trusting a parachute; you get up there and trust the silk, you will find the most wonderful thing in the world, but actually doing it is hard'

Participants reported conflicting advice from HCPs about the risk of adverse events from PA.

'they told me I should never bend forward, never'

The following primary themes emerged from qualitative analysis: [2]

- Patients generally present concerns based on their symptoms or syndromes, not their underlying LTC's.
- Continuity of advice and simple messages reduce confusion and are therefore empowering for people living with LTC's.
- Addressing risk is an essential facilitator for people considering increasing their PA levels
- Cross-sector system support is required to improve the experience of inactive people with LTC's starting to become more physically active.

3. NATIONAL CONSULTATION

Stakeholder consultation with Sport England further informed our understanding of patient preferences through a related piece of work in the UK. In 2019, The National Centre for Sport and Exercise Medicine (NCSEM) at Sheffield Hallam University in collaboration with Sport England and RCGP clinical priority group engaged 361 participants in a national online consultation to inform approaches to improving physical activity support for people with LTCs.[6]

A frequently reported barrier to participation in PA initiatives was getting medical 'sign-off' to participate.

"People who are fit and healthy are told they need to see their GP prior to being able to exercise and this sends the wrong message ... Patients who have a health condition but are safe and well managed should not be asked to see their GP."

Triage processes are often unclear, with a lack of system support for the 'sign-off' process.

"...most aren't qualified to assess the risk for an individual of exercising and the current system doesn't give them the confidence to signpost or refer without fear of them being liable"

People over 50 were more likely to have individual concerns with getting sign-off before participation in PA. Those under 50 emphasised the importance of HCPs having the knowledge, confidence and the right attitudes to have conversations about sport and PA with people with LTC's.

"If you have a health condition, it can be difficult to get medical clearance to participate in certain physical activities. Often this requires sign-off from a health professional, for a fee, who may not even feel qualified or confident to do this."

Finally, our conclusions from our patient and public insight were presented to the Richmond Group of Charities who have done extensive patient facing work in this areas including the '[We are undefeatable](#)' campaign in collaboration with Sport England. The Richmond group confirmed that key themes identified through our consultation process matched commonly held concerns heard reported by their membership groups.

REFERENCES

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