

Successful self-management support for people living with long-term conditions



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Successful self-management programmes for people living long term conditions

Fiona Jones, Professor Rehabilitation Research, St Georges University of London, Founder and CEO Bridges Self-Management





1. What is success?

‘To give the space and power to the patient to problem solve.. to find those solutions...because even though I have those solutions, and I'm sharing with them, those solutions, they won't work. Because they haven't found them for themselves’

Physiotherapist Community Rehab team and Bridges champion

Or is it doing something makes you feel like you?



How can self-management support align with the long-term goal of rehabilitation?



Original Article

 **CLINICAL
REHABILITATION**

Is independence enough? Rehabilitation should include autonomy and social engagement to achieve quality of life

Clinical Rehabilitation
2021, Vol. 35(1) 3–12
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DOI: 10.1177/0269215520954344
journals.sagepub.com/home/cre


John McClure  and Caspian Leah

2. What is self-management?

- Lacks a universal definition
- Somewhere between individualistic and collective responsibility
- Engagement?
- Empowerment?
- Activation?
- Do we all think of it in the same way?



Social Science & Medicine

Volume 176, March 2017, Pages 25-33



Conceptualisation of the ‘good’ self-manager: A qualitative investigation of stakeholder views on the self-management of long-term health conditions

J. Ellis ^a  , E. Boger ^a, S. Latter ^a, A. Kennedy ^b, F. Jones ^c, C. Foster ^d, S. Demain ^a

What it's not...

- It's not DIY
- It's not information giving
- It's not being told what to do

- Common definitions relate to ...'building confidence, skills and knowledge as an individual, as a community and in partnership with healthcare professionals' NHS England 2019



Living with chronic joint pain...what does self-management really mean? Codesign group, September 2022

September - Experience of joint pain/arthritis & anything that worked for them

Main Challenges faced living with arthritis One tip for people experiencing similar challenges

Pain	Unseen effects	Seeing where other people are at	Movement	Yoga	Home remedies	Walking cricket once a week	Gym 3-4 times a week	Take each pain session as it comes
Constant pain and how it affects being able to drive	Very stiff in the morning - putting feet on the ground	Uncertainty - Knee locking when I am walking - not knowing where it might lock	Fearful of falling with hip pain and potential deterioration of health as a result	Raw garlic in the morning	Moving might not always make it worse	Pain killers	Hot water bottle on the painful area	Putting hot water on the painful area
Pain everyday - foot hurting on the top	Night time pain waking me up	Looking normal/great from the outside but inside you are experiencing pain	Being in control of my knee and my care	Not to be bold that it's all in	Believing positive - mind is strong problem is gone	Staying positive - not giving up	Take Cod Liver oil everyday and don't stop	Making things safe around me - eg carpet in the room
Early morning joint pain	Pain impacting on sleep and other responsibilities (being a carer)	Function/day to day	Taking a long time to go and get up in the morning	Plan & pace	Colouring in, mindfulness	Walking 1000 steps a day	Hot bottle baking soda, cinnamon, black pepper	Ginger tea
Pain worse first 2-3 hours in the morning	Getting up in the morning to do the things I need to do	Not been able to drive car	Taking medications as well as other meds	Massages, herbal medicine, think about moving on	Be positive, this too shall pass	Have a group of friends who will understand and support you	Book - if you need help what do you need to do - a go to thing when you aren't thinking straight - everything can spiral out think what you can do if you are in pain	Avoid opioids that is sticking plaster so won't last very long
	Eat spoon of coconut oil	Spikey ball/rollers for foot	Trying not to think about the pain	Talking with friends	Support/community	Doing something for someone else	Playing with grandchildren	Handful of friends you can call upon
							Rubbing with coconut oil - smells good and not bad for your clothes	Get fresh air, keep your weight down, don't give up on gentle exercises

3. Houston we need a theory...

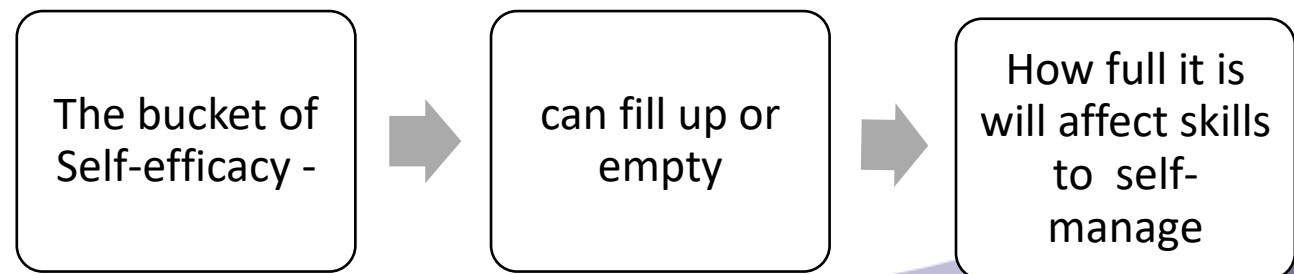
- **Social Cognitive Theory** most commonly theoretical base for self-management programmes
- **Self-efficacy** is ‘An individual’s belief in their own capability to produce a change in a specific behaviour ‘
- Self-efficacy is critical to the success of **self-management**



"Self-efficacy is a **belief** in your **own capability**" –(in other words)
a belief about your **own personal efficacy** (Bandura, 1997)

Why is this important ?

- Self-efficacy is the foundation of motivation, wellbeing and accomplishments
- It is a 'can do' judgement, a sense of personal competence
- It is a cognitive construct which is situation specific (task, context, time)
- It affects motivation and perseverance needed to succeed or get over a set back



Feeling in
control



Out of
control

Self-esteem higher

more likely to give
thing a go

less anxiety

autonomy

more reliance on
support

apathy and worry

feelings of
helplessness

Self-Management

Self-efficacy...the evidence is clear – just 3 examples

1. Related to coping with cancer and quality of life
2. Related to coping with a relative with Alzheimer's
3. Linked to self-management after stroke

1. Chirico A, Lucidi F, Merluzzi T, et al. A meta-analytic review of the relationship of cancer coping self-efficacy with distress and quality of life. *Oncotarget*. 2017;8(22):36800-36811. doi:10.18632/oncotarget.15758

2. Khan TS, Hirschman KB, McHugh MD, Naylor MD. Self-efficacy of family caregivers of older adults with cognitive impairment: A concept analysis. *Nurs Forum*. 2021 Jan;56(1):112-126. doi: 10.1111/nuf.12499. Epub 2020 Sep 4. PMID: 32888197; PMCID: PMC8549654.

3. Fryer CE, Luker JA, McDonnell MN, Hillier SL. Self management programmes for quality of life in people with stroke. *Cochrane Database Syst Rev*. 2016 Aug 22;2016(8):CD010442. doi: 10.1002/14651858.CD010442.pub2. PMID: 27545611; PMCID: PMC6450423.

Self-efficacy is not all about the individual also about the community



- **Confidence in your personal communities** is important for the maintenance of wellbeing, reduction of isolation and mediation of accessing resources
- They are like a **collection of important ties** in which people are embedded through- with different patterns of commitments to family and friends
- Self-management support can **enable people to set up their networks** and personal communities

4. What's the evidence?

'Self-Management Support can lead to significant improvements, in...



knowledge



experience



service use
and costs

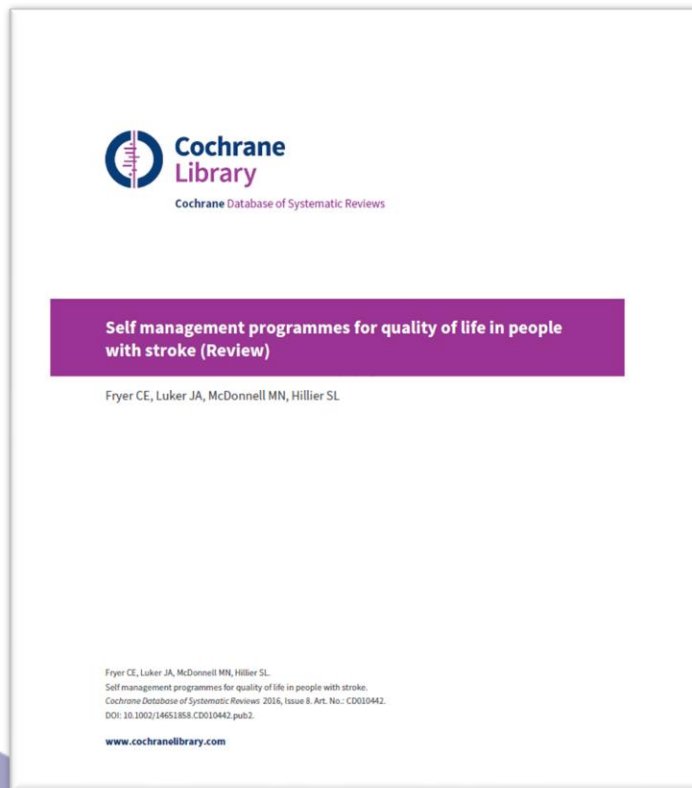


health
behaviours
and outcomes

Reynolds, R., Dennis, S., Hasan, I. *et al.* A systematic review of chronic disease management interventions in primary care. *BMC Fam Pract* **19**, 11 (2018). <https://doi.org/10.1186/s12875-017-0692-3>

Prioritising Patient Care. Supporting Self-Management. National Voices.
https://www.nationalvoices.org.uk/sites/default/files/public/publications/supporting_self-management.pdf

Self-Management support for people with complex conditions the evidence base is building



'Self-management programmes do improve the quality of life after stroke. People with stroke reported improvements in their ability to live the way they wanted and that they felt more empowered to take charge of their lives, rather than be dependent on other people for their happiness and satisfaction with life'

***53 stroke self-management clinical trials currently on ISTRN database

When it works it's a bit like a meandering river....



'The very first session was what do you hope to achieve? She asked me "what do I want to get out of therapy?" '

'As I was saying to [Physiotherapist] the other day, when are you people off? And she said when you feel like you don't need us anymore'

'I would see it (finishing therapy) as a challenge you see. And if I feel something is a challenge, I will try to see if I can overcome that problem'

Jones F, McKeivitt C, Riazi A, *et al*

How is rehabilitation with and without an integrated self-management approach perceived by UK community-dwelling stroke survivors? A qualitative process evaluation to explore implementation and contextual variations

BMJ Open 2017;**7**:e014109. doi: 10.1136/bmjopen-2016-014109

The People 1st Project – integrating self-management support in stroke services across East of England



A mixed-method evaluation led by UEA (Dr Nicola Hancock)

550 healthcare practitioners, across 24 NHS Trusts in the East of England,

Explored how practitioners assimilated and enacted learning from Bridges in their practice, both on an individual and collective basis.

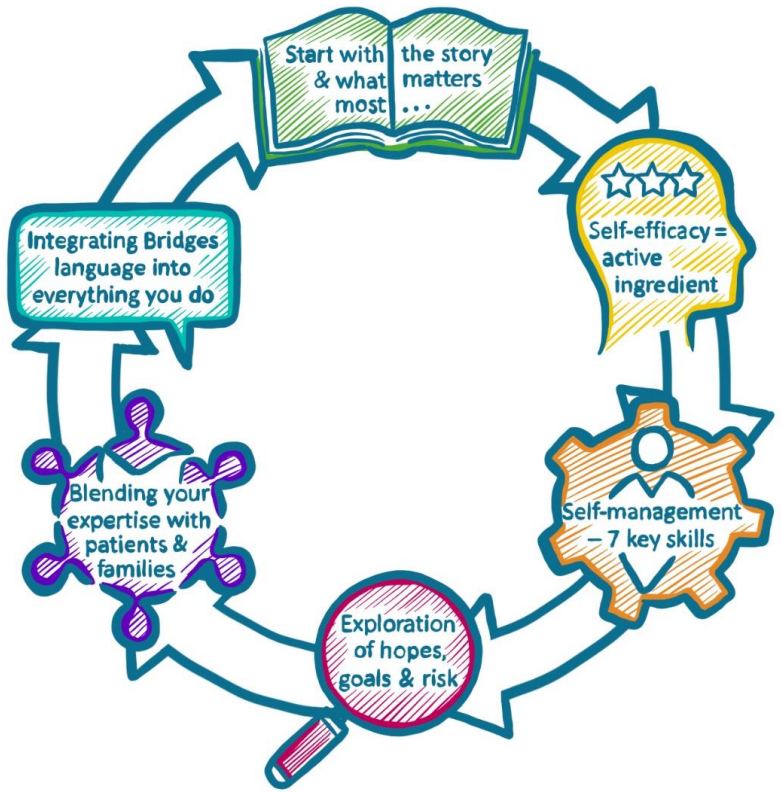
Results showed increase in staff confidence and skill around supported self-management,

Transformations to practice including changes to the structure of, and language used, in patient interactions to place them at the centre of rehabilitation

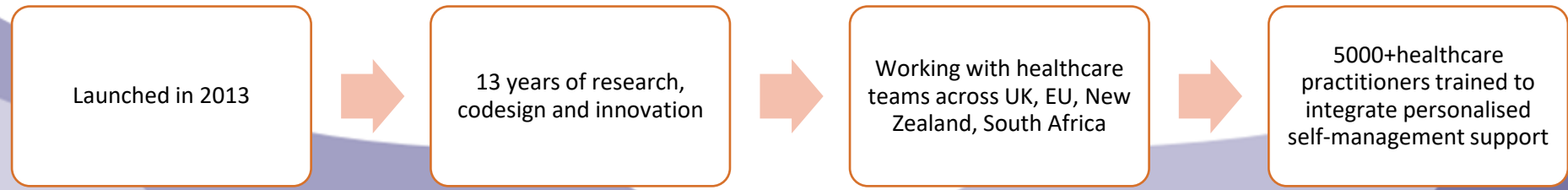
NHS
*Health Education
England*

UEA
University of East Anglia

Example 1 – the story of Bridges ...



Making a change ..with one small step



Started in stroke- changed self-efficacy, QOL, and feasible to integrate into practice

Contextualised to NZ, Australia, South Africa - projects in Sweden and Estonia

Pathway approaches to SMS are possible

- Staff changed attitudes, beliefs, knowledge and skills
- A shared culture/understanding of self-management more efficient

Applied in acute brain injury- feasible to integrate, spread and sustained across 4 Major Trauma centres

Co-designed books for people with NMD, major trauma, Long Covid, TBI Long-term conditions, stroke

Qualitative studies

- Whole systems
- Teams in acute and community settings
- Social care

Applied to Major trauma- staff changed behaviour and processes

Progressive MS - impact on everyday activity, confidence

New areas

- Long Covid
- people with multi-morbidity
- Philippines
- Maternal Medicine

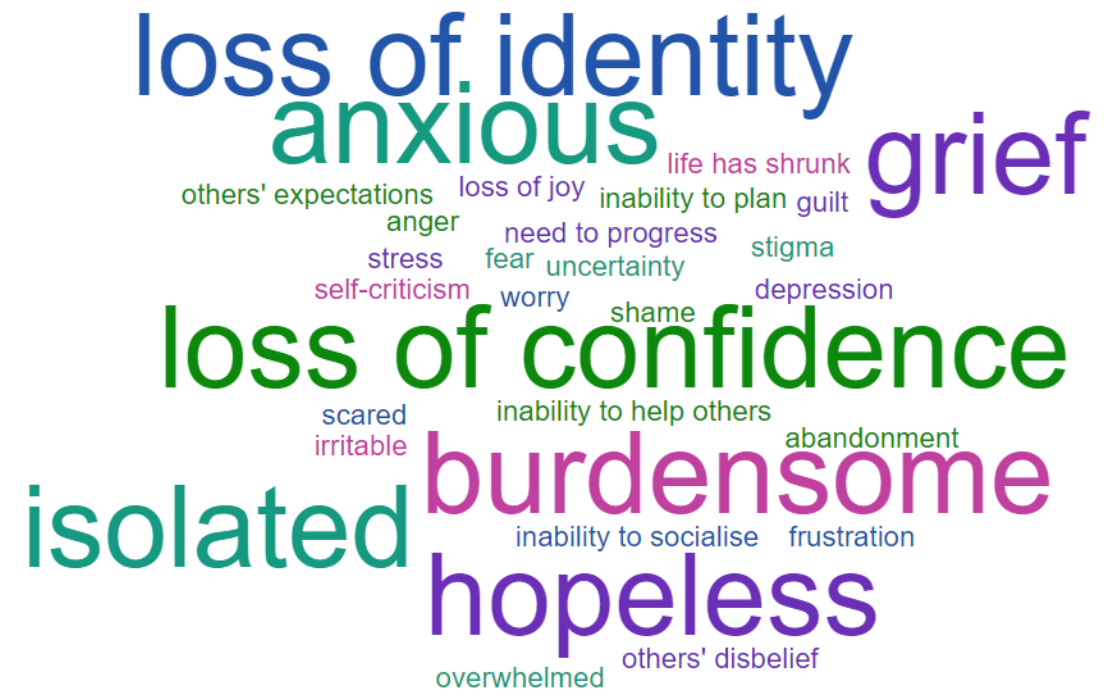
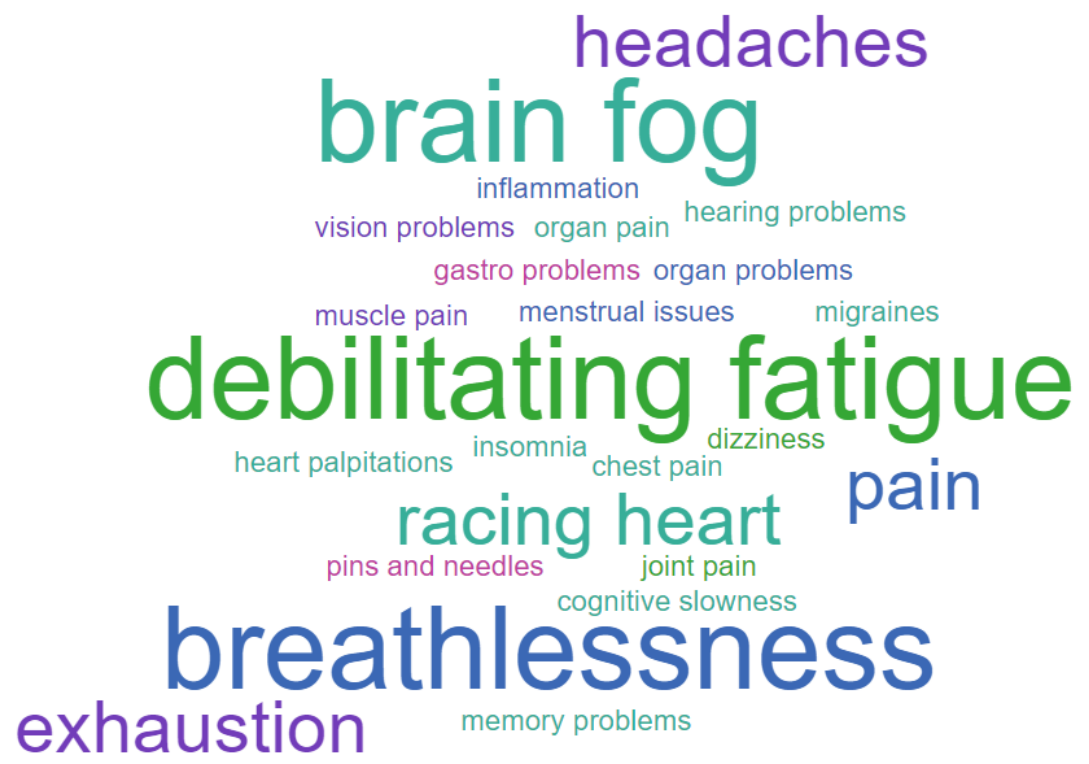
Example 2 – co-designing for long Covid

- **Listen** is a **2-year project** which works in partnership with individuals living with long Covid to **co-design** and **evaluate** a personalised self-management support intervention.
- For people who were **not hospitalised** for Covid and living in England or Wales.
- Reaching people whose **voices are seldom heard** in discussions around long Covid.

Funded by NIHR in July 2021- completes in July 2023

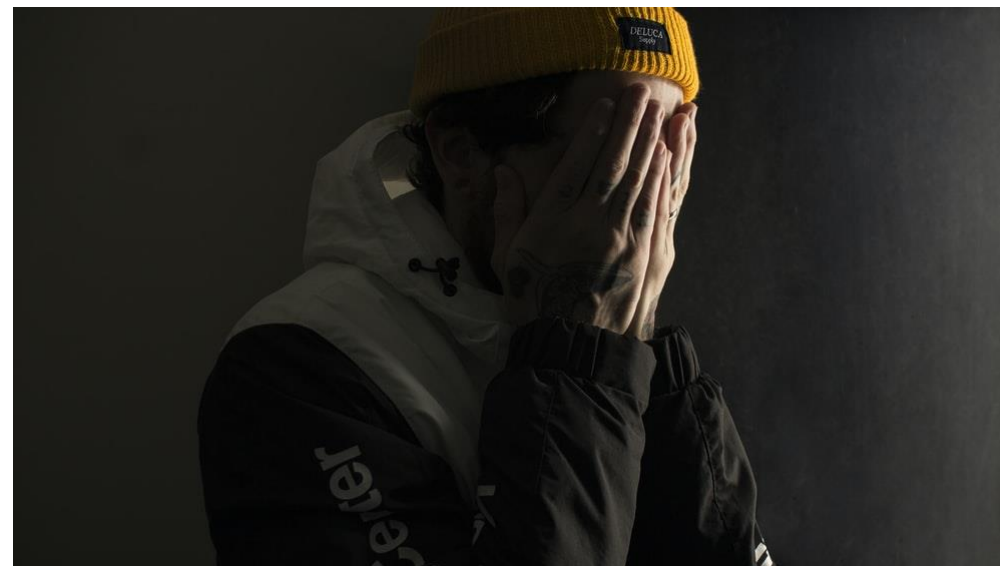


More than 200 symptoms described ...



People living with or recovering from long Covid have been central to “Listen”

“your world is shrunk, and you feel like the worst version of yourself. You feel shame – shame that you’re not better, and that you're failing at getting better” Codesign participant October 21



VOICES Long Covid19 Research
Involvement Hub



Covid19 Public Research
Panel



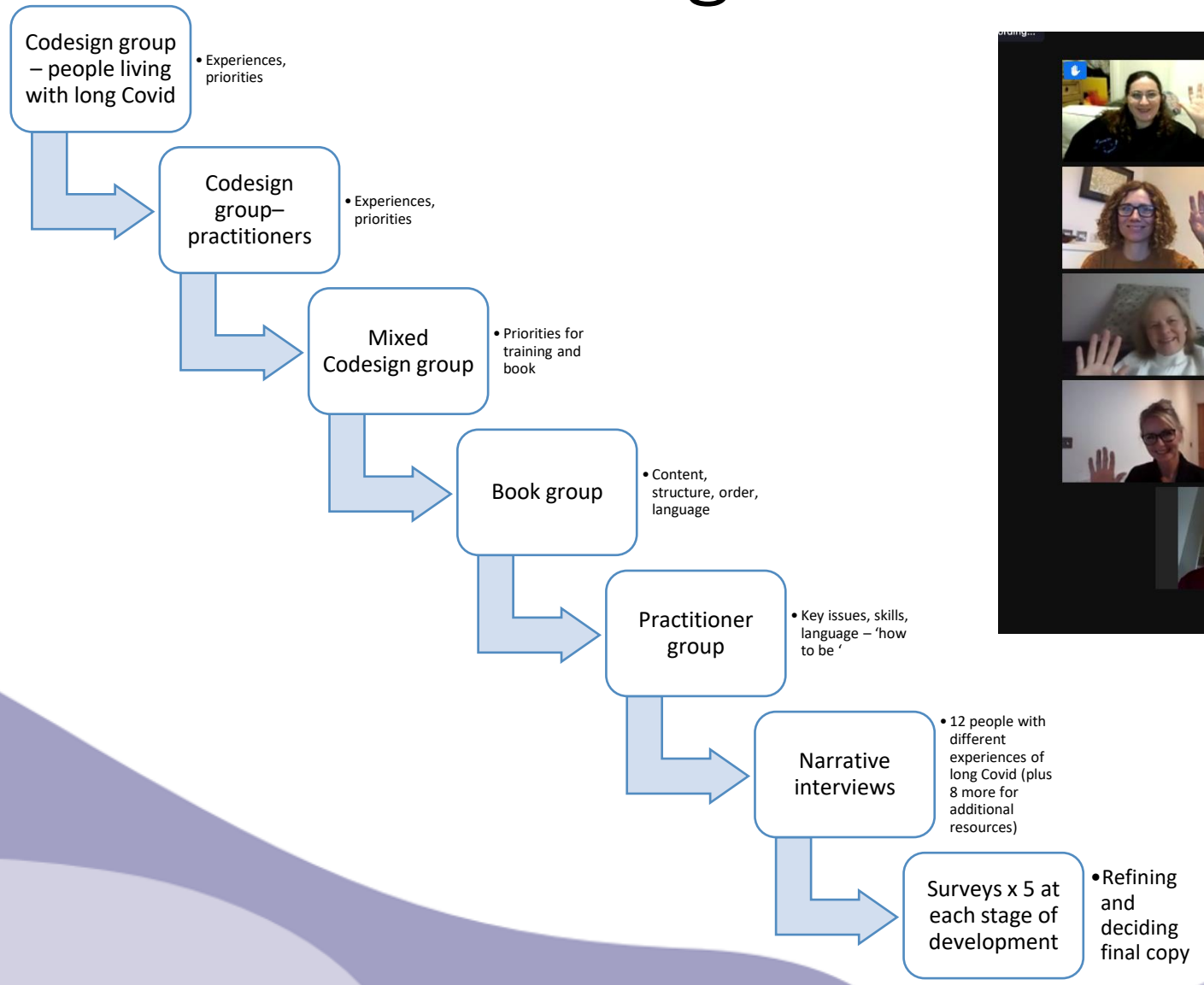
What NICE guidance says

Give advice and information on self-management to people with ongoing symptomatic COVID-19 or post-COVID-19 syndrome, starting from their initial assessment. This should include:

1. Ways to self-manage their symptoms, such as setting realistic goals
2. Who to contact if they are worried about their symptoms or they need support with self-management
3. Sources of advice and support, including support groups, social prescribing, online forums and apps
4. How to get support from other services, including social care, housing, and employment, and advice about financial support
5. Information about new or continuing symptoms of COVID-19 that the person can share with their family, carers and friends



Listen codesign..



Some advice to you all from our codesign groups...



Reflect upon your choice of **language**. Avoid throw away comments like ‘you’ll be fine soon’



Re-conceptualise progress and success. Setbacks and uncertainty are normal, and linear recovery should not be expected so plateaus and stability should be accepted as progress.



Try to **move away from prescribing** and finding strategies and solutions. **“Try get comfortable with the discomfort of it”,**



Listen and **validate** patients’ experiences. Just providing a listening ear and believing that the condition is real is huge. This will help to **build trust in your therapeutic relationship** which is necessary to support confidence and problem.

A wooden signpost made of two dark brown planks. The top plank is horizontal and has the words "Easier Way" written in white, cursive-style paint. The bottom plank is vertical and has a white arrow painted on it, pointing to the left. The signpost is mounted on a wooden post. The background is a blurred green field.

Easier Way

Take home messages from people that know...

Remember not everyone likes the word goals or self-management....



The power of the tick and big dreams



Encouraging feelings of success



Link success to individuals own effort



Consider how the self-efficacy bucket will fill up



How can someone record and monitor their own success



And spend time reflecting on the feeling when you get there...

Thank you for listening...

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@bridgesselfmgmt



THE COMPLEXITY CHALLENGE

A CSP SUMMIT

What are the views of physiotherapists regarding their role in self-management approaches?

Dr Clare Killingback



Reflection: on your own



It's my job as the
physiotherapist to
manage people's
conditions



It's my job as the
physiotherapist to
support people in
managing well with
their condition(s)

Self-management is on trend

Personalisation



What did we do?

1. A **systematic review** on physiotherapists' views on their role in self-management approaches
2. A **qualitative study** on falls service practitioners and how they help people transition to long-term self-management of falls
3. A **narrative inquiry** study of the role of person-centred practice in physiotherapy

What did we find?

Systematic review

- For self-management approaches to work, physiotherapists believe that patients need to **actively participate**
- Boundaries on **who is the expert** were blurred at times with some physiotherapists struggling to relinquish control
- **High-quality patient-therapist relationships** are required to build trust in order to support patients in self-managing their long-term conditions
- **Competing paradigms** in which a service is delivered may facilitate or hinder self-management
- **Seeing patients as people** is integral to supporting self-management approaches

Views of falls service practitioners re self-management

- They sought to take a **person-centred approach** to engage patients in self-management of falls prevention exercises
- Providing **information and signposting to exercise opportunities** was viewed as being within their scope

Narrative inquiry: role of person-centred practice in physiotherapy

- Physiotherapists who are **more person-centred in practice were better placed to promote self-management** of long-term conditions

What does this mean for us?

- Where do the boundaries of expertise lie between the patient and therapist?
- How do we conceptualise self-management?
- What is the healthcare paradigm of the environment where you work?
- Do we view patients as people with whole lives – not just the bit that we are dealing with?

Where do we go from here?

- Physiotherapists often feel they lack skills in self-management
- How do we upskill in this area?
- I focus on those who are pre-registration
- How do we equip others?

Finally, a plea to how we teach self-management in our pre-registration programmes

- We've embedded it in our learning outcomes
- Teach the skill of health coaching early on
- Challenge students on who is the expert
- Involve service users and carers
- Strong emphasis on person-centred practice
- I'd love to connect with other educators on how we develop self-management approaches in our students C.Killingback@hull.ac.uk



THE COMPLEXITY CHALLENGE

A CSP SUMMIT



19 > OCT > 2022

Self-management support: frameworks and identification tools

Dr Nathan Hutting



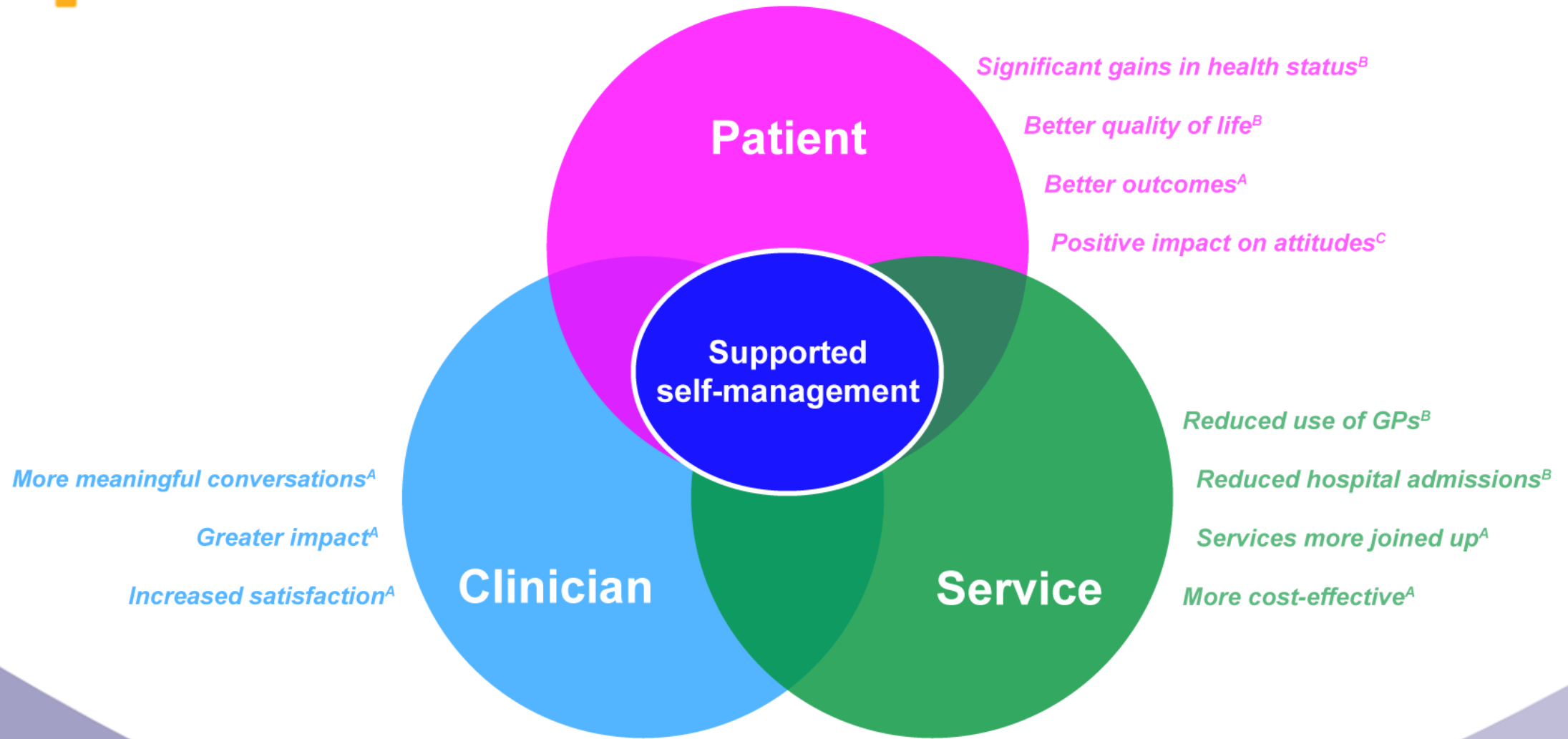
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OF APPLIED SCIENCES**

Self-management Support

Self-management support is the help given to people with chronic conditions that enables them to manage their health on a day-to-day basis.

Self-management support can help and inspire people to learn more about their conditions and to take an active role in their health care.





Highlights

- Physiotherapists believe that self-management support is important in people with low back pain.
- Physiotherapists do not fully integrate support with regard to important self-management skills.
- Integrating self-management support is often difficult and does not work well enough for all patients.
- The most important barrier with regard to integrating self-management was patient expectations.
- Physiotherapists need knowledge, opportunities to exchange experiences and tools for patients.

Highlights

- Therapists mainly provided patient education rather than self-management support.
- They mainly focused on the physical and biomechanical factors of the condition.
- Important self-management skills are generally not addressed sufficiently.
- Respondents had needs with regard to providing self-management support.



Contents lists available at [ScienceDirect](#)

Musculoskeletal Science and Practice

journal homepage: www.elsevier.com/locate/msksp



NATHAN HUTTING, PT, PhD¹ • VENERINA JOHNSTON, PT, PhD^{2,3}
J. BART STAAL, PT, PhD^{4,5} • YVONNE F. HEERKENS, PhD¹

Promoting the Use of Self-management Strategies for People With Persistent Musculoskeletal Disorders: The Role of Physical Therapists

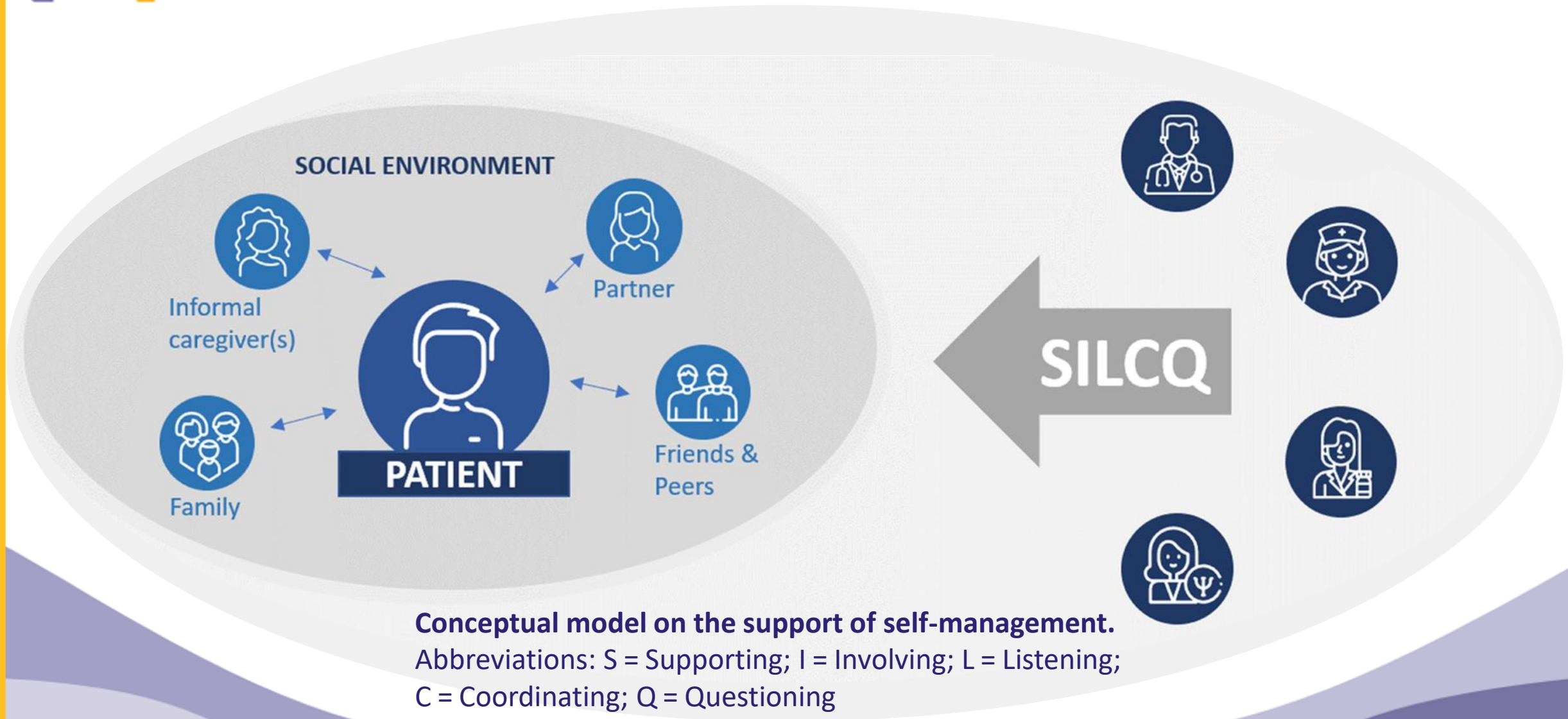
[J Orthop Sports Phys Ther 2019;49\(4\):212-215. doi:10.2519/jospt.2019.0605](#)

Physical therapists should use a self-management approach to individualized (physical therapy) treatment for patients with persistent musculoskeletal disorders whenever possible.

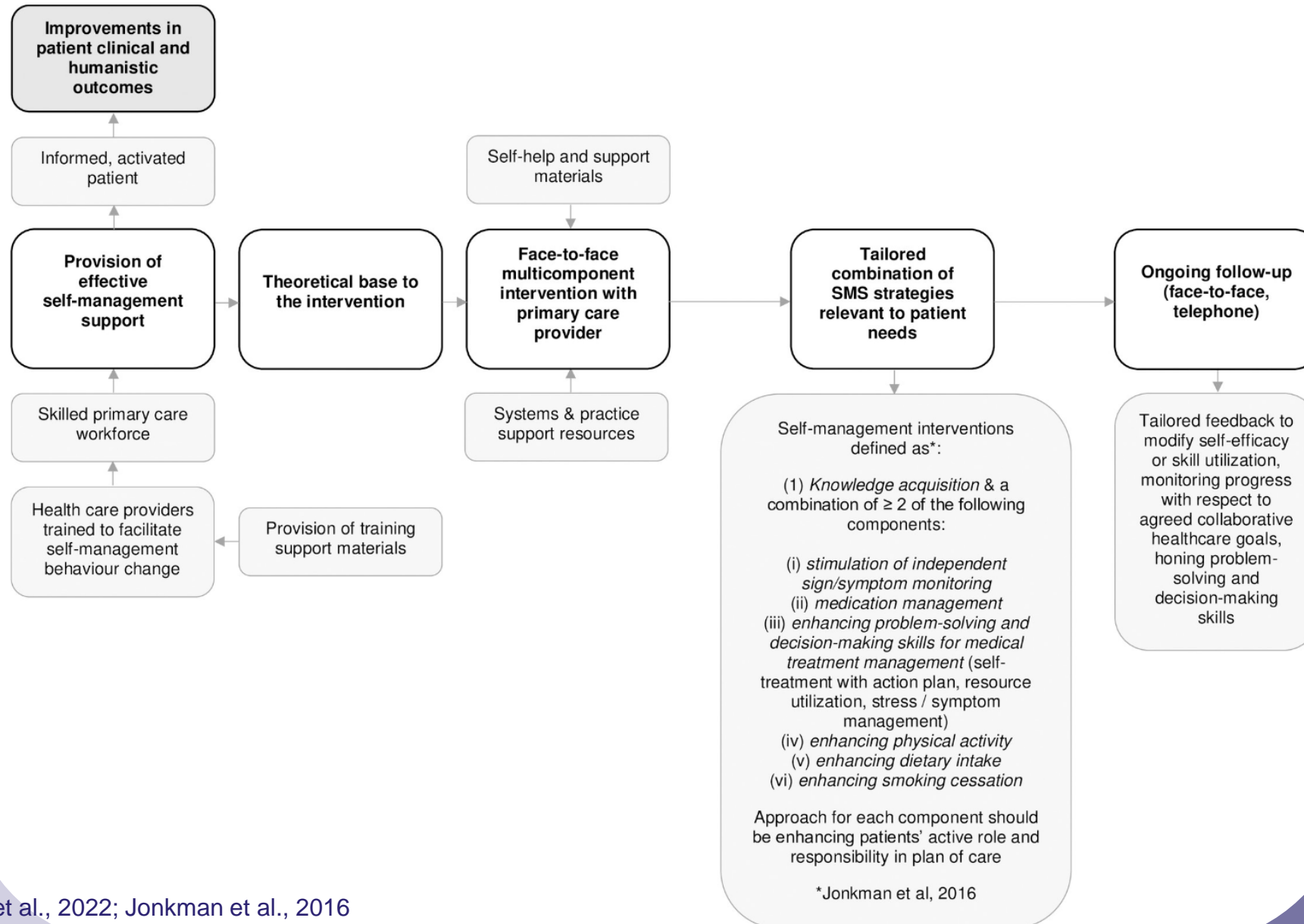


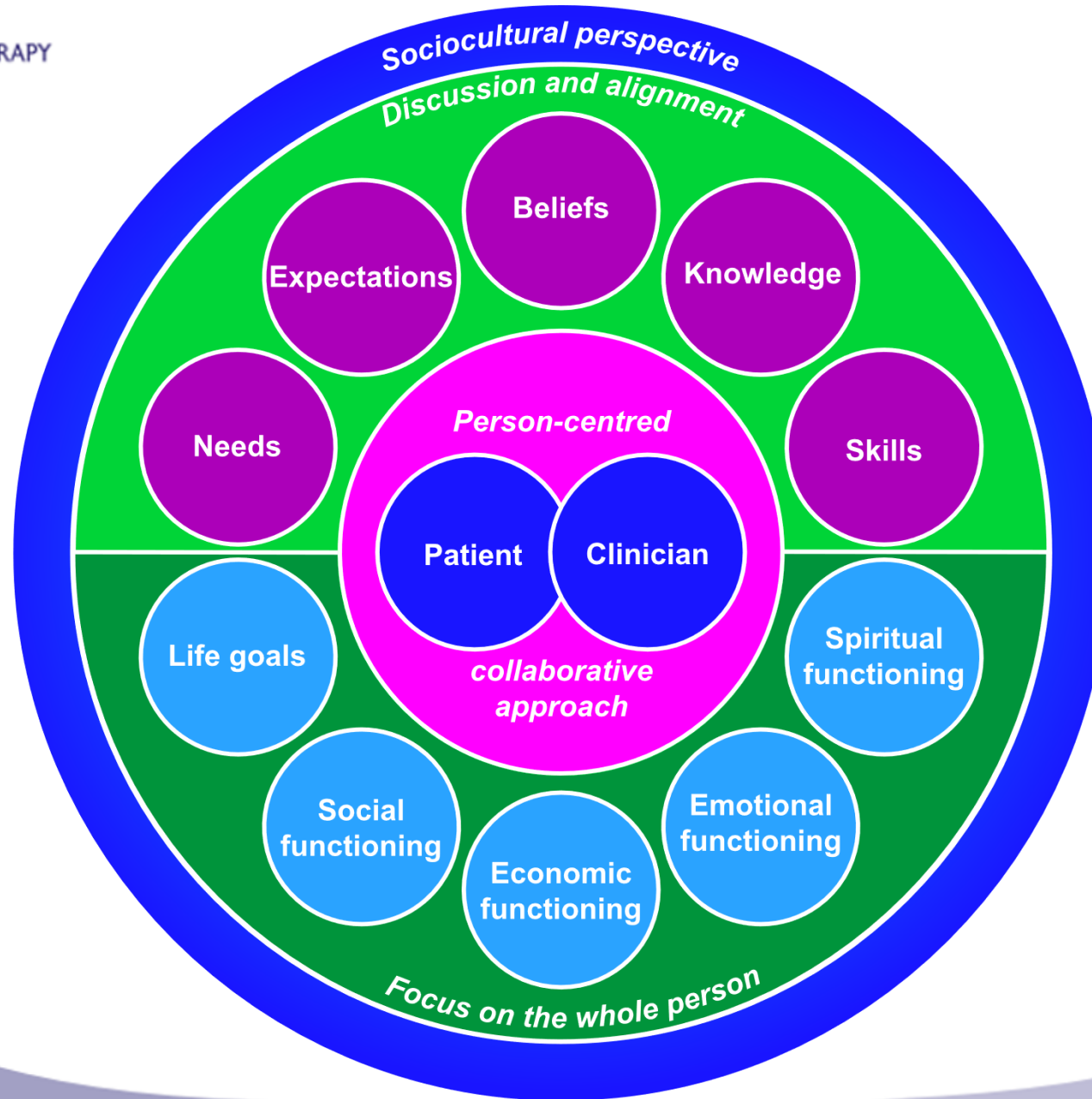
Self-management Support



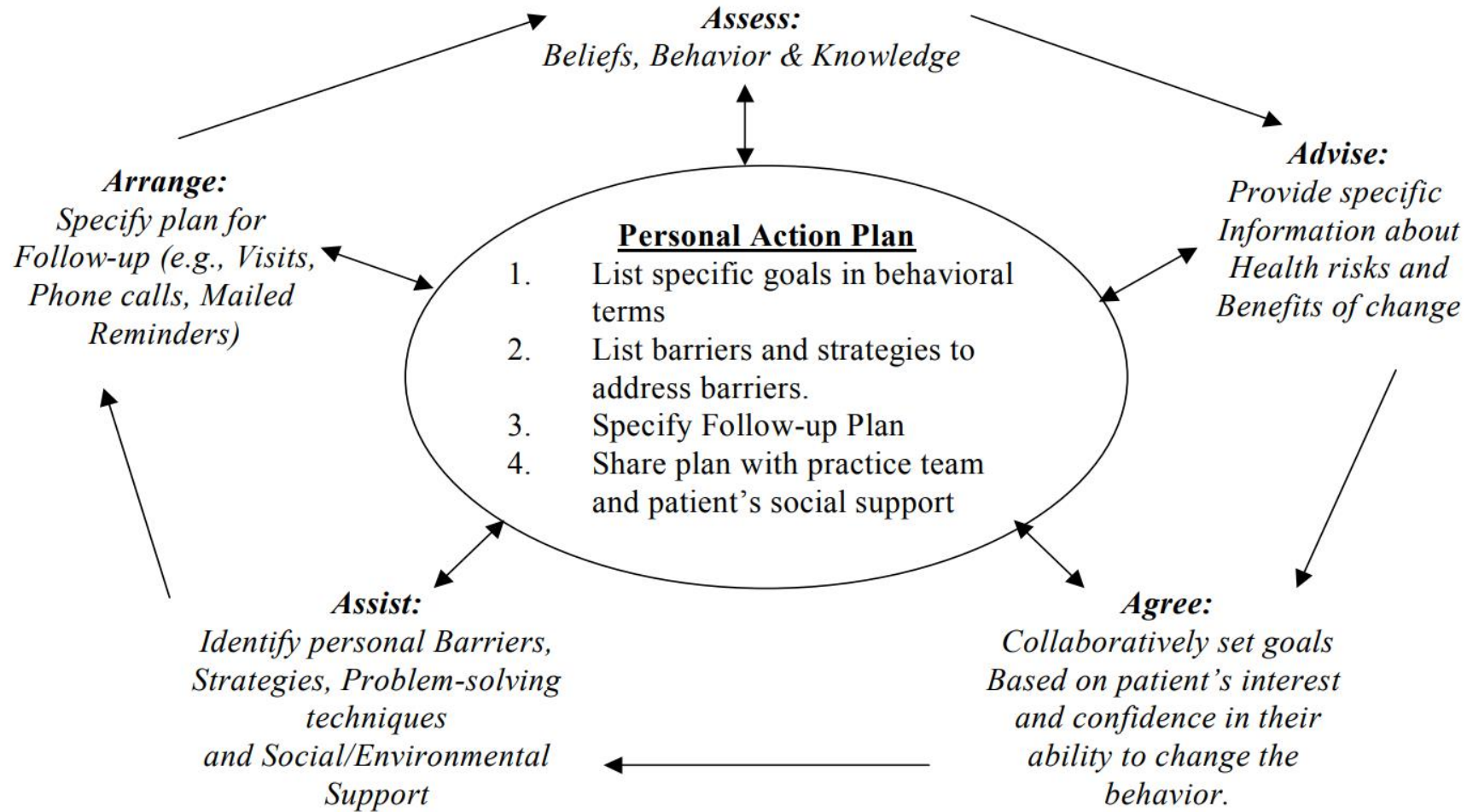


Conceptual model on the support of self-management.
Abbreviations: S = Supporting; I = Involving; L = Listening;
C = Coordinating; Q = Questioning





Self-Management Model with 5 A's (Glasgow, et al, 2002; Whitlock, et al, 2002)



Self-management attributes

Person-oriented attributes

1. The person must **actively take part** in the care process.
2. The person must take **responsibility** for the care process.
3. The person must have a **positive way of coping** with adversity.

Person-environment-oriented attributes

4. The person must be **correctly informed** about the condition, disease and treatment.
5. Self-management is **individually defined** and entails **expressing needs, values and priorities**.
6. Self-management entails **openness** to ensure a **reciprocal partnership** with healthcare providers.
7. Self-management entails **openness to social support**.

Summarising attributes

8. Self-management is a **lifetime task**.
9. Self-management assumes **personal skills**:
 - 9.1 **Problem-solving**;
 - 9.2 **Decision-making**;
 - 9.3 **Using resources**;
 - 9.4 Forming a **patient-healthcare provider partnership**;
 - 9.5 **Goal setting** and **evaluating the attainment** of the goals.
10. Self-management encompasses medical, role and emotional domains:
 - 10.1 Medical management;
 - 10.2 Role-management;
 - 10.3 Emotional management.

Self-management vs education

Patient education	Self-management
Provides information and teaches technical disease-related skills	Teaches skills on how to act on problems
Problems covered are widespread common problems related to a specific disease	Problems covered are identified by the patient
Disease specific and offers information and technical skills related to the disease	Provides problem-solving skills that are relevant to the consequences of chronic conditions in general
Based on the underlying theory that disease-specific knowledge creates behavior change , which in turn produces better outcomes	Based on the theory that greater patient confidence in their capacity to make life-improving changes yields better clinical outcomes
Goal is compliance	Goal is increased self-efficacy and improved clinical outcomes
Health professional is the educator	Educators may be health professionals, peer leaders, or other patients

World Physiotherapy Congress 2021 online 9–11 April

Focused symposium #WorldPhysio2021

Patient-centred care for people with musculoskeletal conditions



Nathan Hutting
Netherlands



JP Caneiro
Australia



Maxi Miciak
Canada



Lisa Roberts
United Kingdom



Otieno Martin Ong'wen
Kenya

congress.physio/2021/programme/fs/FS-01

Musculoskeletal Science and Practice 57 (2022) 102434



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Patient-centered care in musculoskeletal practice: Key elements to support clinicians to focus on the person

Nathan Hutting^{a,*}, J.P. Caneiro^b, Otieno Martin Ong'wen^c, Maxi Miciak^d, Lisa Roberts^{e,f}



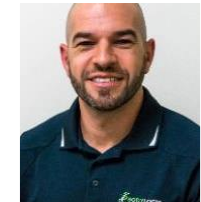
Musculoskeletal Science and Practice 62 (2022) 102663



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Person-centered care for musculoskeletal pain: Putting principles into practice

Nathan Hutting^{a,*}, J.P. Caneiro^b, Otieno Martin Ong'wen^c, Maxi Miciak^d, Lisa Roberts^{e,f}



Biopsychosocial understanding of
the person's experience

Person-focused communication

Supported
self-management

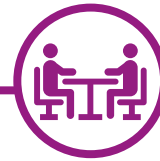


Therapeutic relationship



Identification and goal setting

Identification
Shared decision making
Goal setting



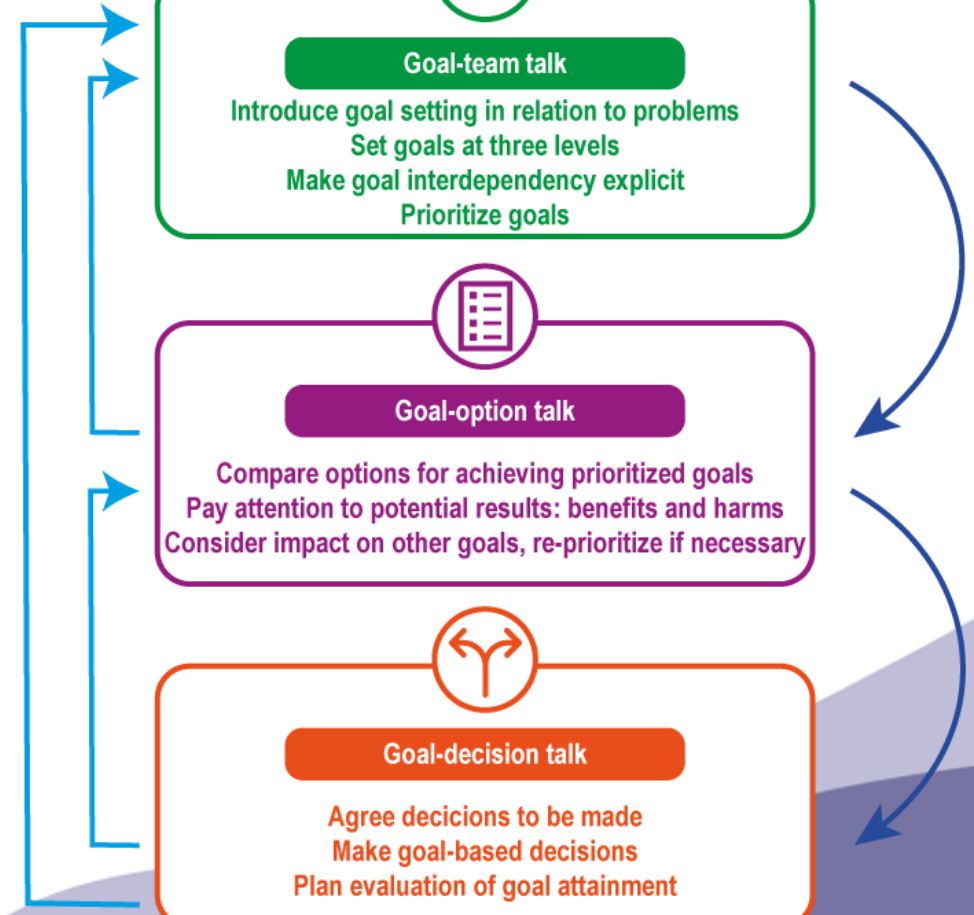
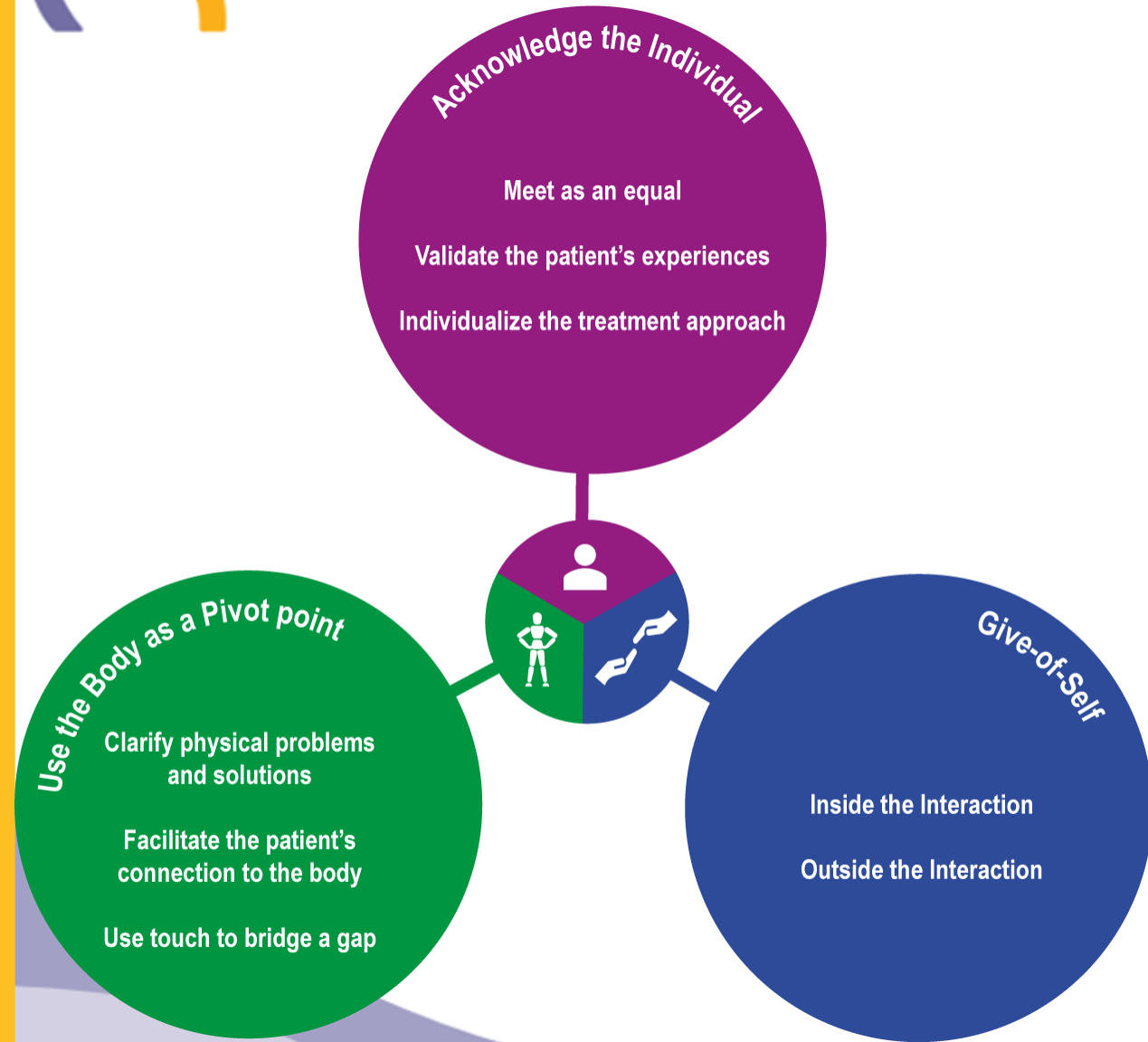
Coaching to self-management

General self-management skills
Specific knowledge, skills and tools
(including overcoming barriers)



Evaluation

Evaluating goals
Planning for the future
Follow-up plan



Identification and goal setting

- Identification
- Shared decision making
- Goal setting

Coaching to self-management

- General self-management skills
- Specific knowledge, skills and tools (including overcoming barriers)

Evaluation

- Evaluating goals
- Planning for the future
- Follow-up plan



Attitude



Self-efficacy



Social influence



Knowledge



Skills



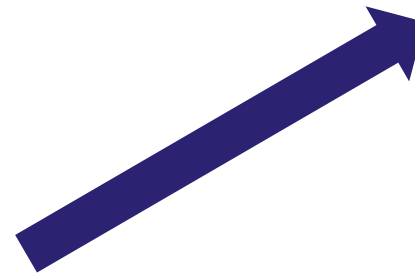
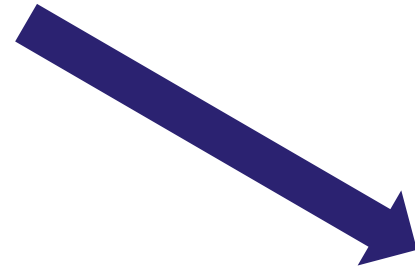
Attitude



Self-efficacy



Social
influence



Intention,
Action planning

Barriers



Behaviour



Knowledge



Skills

Welkom



Welkom op de website van SterQ aan het Werk

SterQ aan het Werk is een online programma voor mensen die een infectieziekte hebben doorgemaakt, zoals bijvoorbeeld Q-koorts, covid-19/corona, of de ziekte van Lyme. Het programma biedt ondersteuning bij het werken en aan het werk blijven met een infectieziekte.

Inloggen

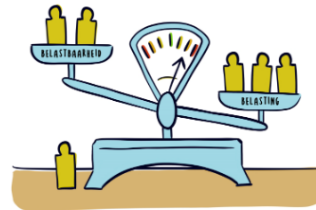
Registreren

Hoe werkt het?

Het programma bestaat uit zes modules die u stapsgewijs door het programma heen leiden. In de modules krijgt u informatie en tips over hoe met (de gevolgen van) een infectieziekte om te gaan. Elke module duurt ongeveer 30 minuten.

Het programma bestaat uit de volgende modules:

1. Op zoek naar balans
2. Zorg voor voldoende energie
3. Acceptatie en omgaan met klachten en onbegrip
4. Mijn werksituatie
5. Werkwensen en aanpassingen
6. Ondersteuning en gesprekken



Door het maken van opdrachten krijgt u ook een beter inzicht in uw eigen situatie en leert u vaardigheden om beter met de gevolgen van uw klachten of beperkingen om te gaan.

SterQ aan het Werk

Het programma is ontwikkeld binnen het project SterQ aan het Werk. Het programma is ontwikkeld door experts, in samenwerking met ervaringsdeskundigen. De modules zijn gedeeltelijk gebaseerd op een eerder ontwikkelde *werkwijzer* voor mensen met Q-koorts.

SterQ aan het Werk is een project van de Hogeschool van Arnhem en Nijmegen, Centrum Werk Gezondheid, Q-support, Q-uestion en C-support. Het project is gesubsidieerd door ZonMw.

Voor wie is het programma?

Het programma richt zich op mensen met een infectieziekte, maar ook mensen die een andere (chronische) aandoening hebben, kunnen het programma gebruiken.

De modules richten zich vooral op mensen die nog aan het werk zijn. In een eerder ontwikkelde *werkwijzer* is ook ruimschoots aandacht voor mensen die zich ziek gemeld hebben, een WIA-uitkering gaan aanvragen of werkzoekend zijn.



Meer informatie

Voor meer informatie kunt u terecht bij:

- Uw huisarts
- Uw bedrijfsarts en/of fysiotherapie op het werk
- [Thuisarts.nl](https://www.thuisarts.nl)
- [Q-koorts.nl](https://www.q-koorts.nl)
- C-support
- Q-support
- Q-uestion
- Lymevereniging
- *Werkwijzer*

Vragen of opmerkingen over het programma?

Mail ons



Thank you for your attention

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