



RCSI

Patient centricity in Irish healthcare – How to make it work?

September 15th 2022

‘Sharing perspectives – PPI and patient centric
research’

Frances Horgan RCSI Physiotherapy

RCSI DEVELOPING HEALTHCARE LEADERS WHO MAKE A DIFFERENCE WORLDWIDE

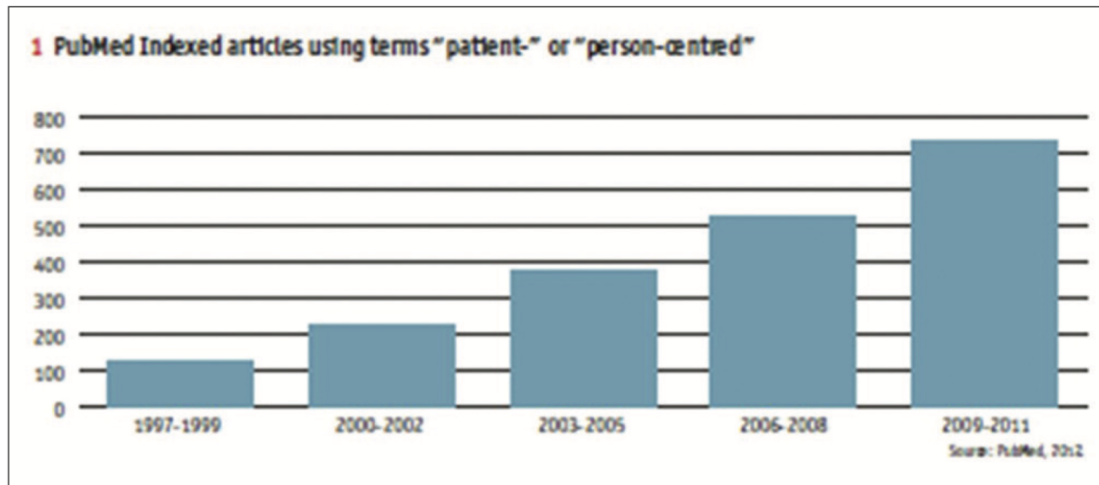


A Patient Centric approach

- Patient centricity is defined as:
- *'Putting the patient first in an open and sustained engagement to respectfully and compassionately achieve the best experience and outcome for that person and their family'*



Patient centric approach in clinical trials



six-fold increase in the last 12 years related to a number of searches related to the term “patient-centred” in PubMed

Figure 1: The graph depicts a six-fold increase in the last 12 years related to a number of searches related to the term “patient-centered” in PubMed. It is indicative of the curiosity and awareness that exists in the industry for this concept. Reference for this is “Reinventing Biopharma: Strategies for an evolving marketplace, The Patient Led R and D strategy, An Economist Intelligence Unit report Sponsored by Quintiles.” Available from: <http://www.quintiles.com/~media/library/white%20papers/reinventing-biopharma-strategies-for-an-evolving-marketplace-the-patient-led-rampd-strategy.pdf>

Reference <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4504054/pdf/PCR-6-134.pdf>

Patient CentricityPublic and Patient Involvement (PPI)

- INVOLVE defines public involvement in research as research being carried out **'with' or 'by' members of the public** rather than 'to', 'about' or 'for' them. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials, undertaking interviews with research participants.
- When using the term **'public'** we include patients, potential patients, carers and people who use health and social care services as well as people from organisations that represent people who use services.
- Whilst all of us are actual, former or indeed potential users of health and social care services, there is an important distinction to be made between the *perspectives of the public and the perspectives of people who have a professional role in health and social care services*

National HRB - PPI Ignite Network – The Vision

By promoting excellence and innovation in PPI, the HRB PPI IGNITE Network will become an important contributor to improved outcomes for the public.

“PPI is occurring when individuals **meaningfully and actively collaborate** in the governance, priority setting, and conduct of research, as well as in summarising, distributing, sharing and applying its resulting knowledge”



Public and Patient Involvement

doi: 10.1111/hex.12523

Editorial Briefing

Public and patient involvement in health policy: A continuously growing field

During the past decades, increased attention has been given to public and patient involvement in health policy. Public involvement has been defined as the involvement of lay people in strategic decision about health services and policy at the local or national level. Concomitantly, patient involvement refers to the inclusion of patients in decision making concerning their

and thus achieve better recruitment and data collection in care homes. From research area to health care, *Xesfingi et al.* report on the discrepancy between citizens' preferences and actual public spending with regard to the resources allocated to the functions of "curative care services" as well as "medical goods and services dispensed to outpatients" in Greece. They high-

Ní Shé *et al.* *Research Involvement and Engagement* (2020) 6:46
<https://doi.org/10.1186/s40900-020-00220-7>

Research Involvement
and Engagement

RESEARCH ARTICLE

Open Access

Minding the gap: identifying values to enable public and patient involvement at the pre-commencement stage of research projects



Éidín Ní Shé^{1*}, Jennifer Cassidy², Carmel Davies¹, Aoife De Brún¹, Sarah Donnelly³, Emma Dorris⁴, Nikki Dunne⁵, Karen Egan⁶, Michel Foley⁷, Mary Galvin⁸, Mary Harkin⁹, Martha Killilea¹⁰, Thilo Kroll¹, Vanessa Lacey¹¹, Veronica Lambert¹², Sarah McLoughlin⁶, Derick Mitchell¹³, Edel Murphy¹⁰, Purity Mwendwa¹, Emma Nicholson¹, Deirdre O'Donnell¹ and Laura O'Phillbin¹⁴

REVIEW ARTICLE

Clarifying the mechanisms and resources that enable the reciprocal involvement of seldom heard groups in health and social care research: A collaborative rapid realist review process

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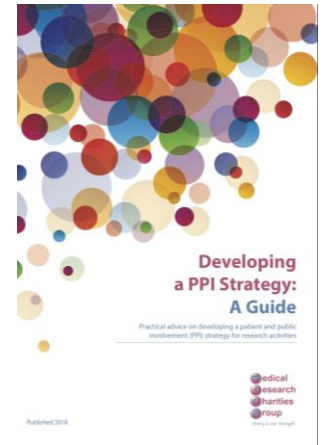
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Study Protocol

A protocol for the evaluation of the process and impact of embedding formal and experiential Public and Patient Involvement training in a structured PhD programme

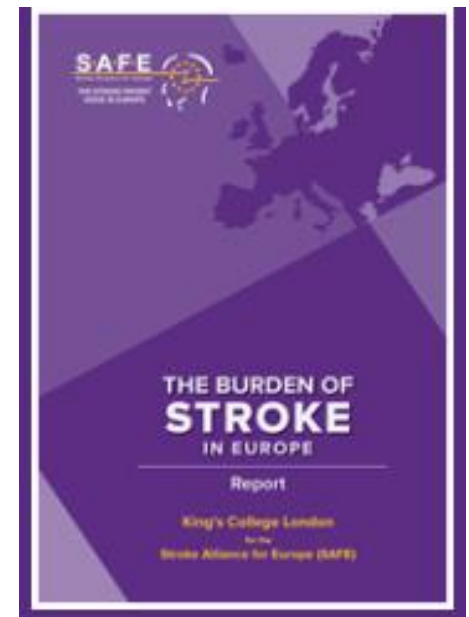
Louise Foley¹, Bridget Kiely², Aisling Croke², James Larkin², Susan M Smith², Barbara Clyne², Maria Pierce³, Edel Murphy⁴ and on behalf of the Collaborative Doctoral Award in Multimorbidity (CDA-MM) Team



The Burden of Stroke



- Between 2015 and 2035, there will be a 34% increase in total number of **stroke events** in the EU from 613,148 in 2015 to 819,771 in 2035
- Total **cost of stroke** in the EU - estimated 45 billion euros in 2015 set to rise, including both healthcare and non-healthcare costs
- The number of people **living with stroke as a chronic condition** will rise from 3,718,785 in 2015 to 4,631,050 in 2035, representing an increase of 25% or almost one million people across Europe
- <http://www.safestroke.eu/burden-of-stroke/>



KEY FINDINGS 2019

20
HOSPITALS



4275
PATIENTS RECORDED

83%
DATA COVERAGE

WHO HAS A STROKE?
The average age of patients with a stroke was 72 years and 24% were aged under 65 years.



10.6%

Thrombolysis is the breakdown of blood clots formed in blood vessels using medication. It can only be given within 4.5-hours of onset of stroke symptoms. In 2019, 10.6% of patients with ischaemic stroke had treatment with thrombolysis.

9%

Thrombectomy (EVT) is a procedure where large clots can be removed from arteries in the brain. In 2019, 9% of patients with a stroke had a thrombectomy. The rate of thrombectomy in Europe is 2%.

STROKE UNIT CARE

A stroke unit is a ward or area within a hospital where patients with a stroke are cared for by multidisciplinary teams with expertise in managing patients with a stroke.



71% of patients were admitted to a stroke unit.



The median length of stay in a stroke unit was **8 days**.



67% of patients had a swallow screen performed.



22% of patients had a mood screen performed.

OUTCOMES



72% of patients with ischaemic stroke and 62% of patients with haemorrhagic stroke had disabilities on discharge.



51% of patients with a stroke were discharged home.



5% of patients with a stroke were discharged home with Early Supported Discharge (ESD) - stroke specific rehabilitation in the home setting. 8% of patients with a stroke were discharged to long term care.



Mortality rate for ischaemic stroke mortality is 9% and 31% in haemorrhagic stroke.

MULTIDISCIPLINARY TEAM ASSESSMENTS



| | | |
|---|---|--------------------------------------|
| Clinical nurse specialist in stroke 84% | Speech and language therapist 66% | Occupational therapist 83% |
| Dietician 33% | Physiotherapist 92% | Psychologist 4% |

TIME IS BRAIN - EMERGENCY CARE



49% of patients arrived at hospital within 3 hours from onset of stroke symptoms.



66% of patients were seen by a doctor within 1 hour of arrival at hospital



44% of CT scans were performed within 1 hour of arrival at hospital



The median time between arrival at hospital and treatment with thrombolysis 56 minutes

THE HEALTH AND SOCIAL CARE PROFESSIONAL (HSCP) DATASET

The HSCP dataset was developed by the NSP in collaboration with the professional bodies for physiotherapy, occupational therapy, and speech and language therapy. The data represents additional rehabilitation information from 1,604 physiotherapy cases, 1,944 occupational therapy cases and 993 speech and language therapy cases in 17 participating hospitals. It is not a representation of rehabilitation for all patients with stroke.



Within the HSCP dataset Physiotherapists, Occupational therapists and Speech and language therapists reported that:



More than **50%** of patients did not receive sufficient therapy.

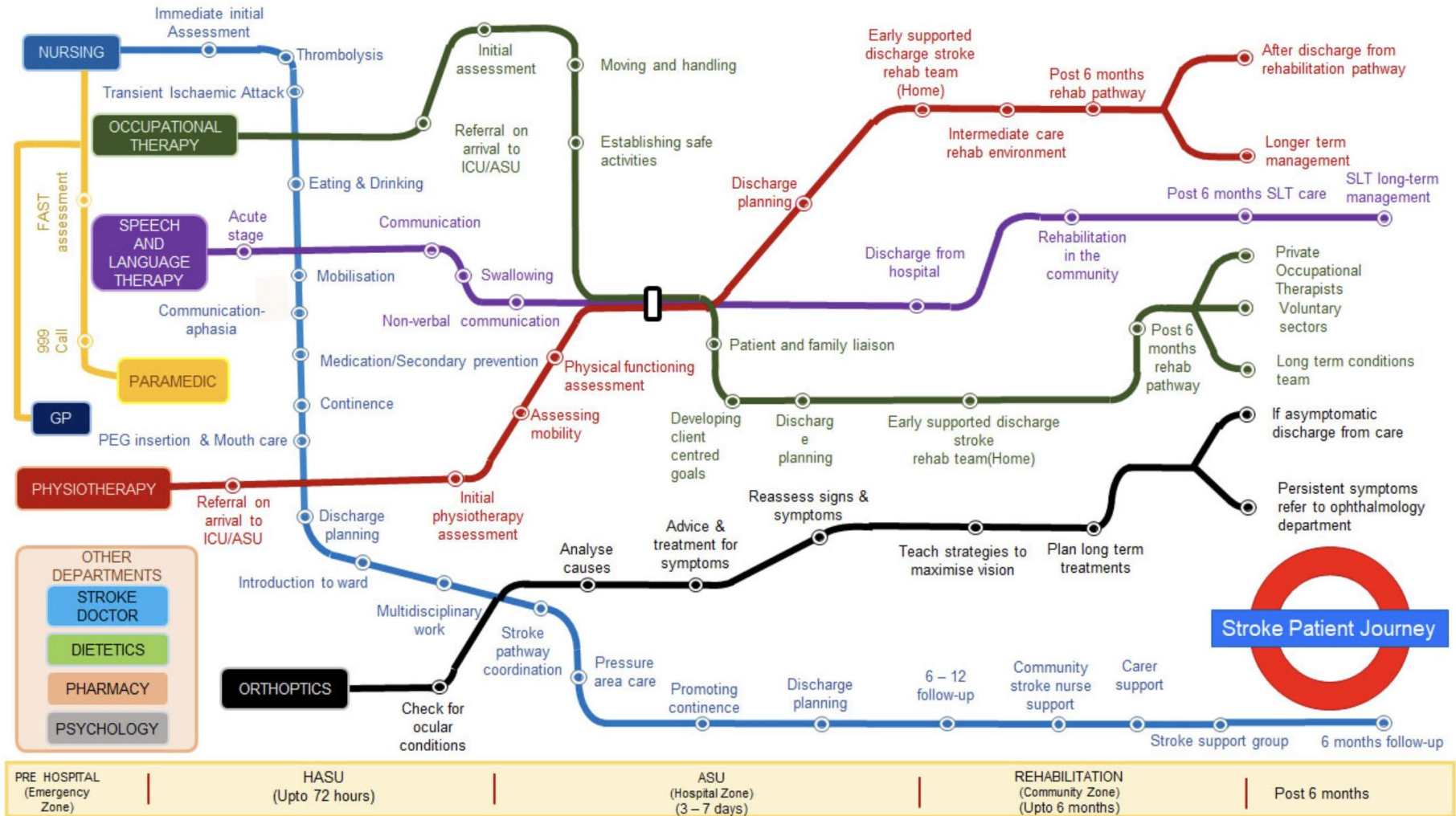


Approximately **50%** of their patient groups required follow-up therapy on discharge.

HSE National Clinical Programme for Stroke Care, 2021-25 – Five Year (costed) Strategy

- The aim of the work of this group will be to decide what can be realistically delivered in the area of stroke rehabilitation in Ireland over the next 5-years, that will have greatest impact and should be prioritised.
- **1 Acute Stroke Care**
- **2 Stroke Prevention**
- **3. Rehabilitation and Restoration to Living**
- **4. Education and Research**

Stroke Patient Journey



<http://strokepatientjourney.co.uk>

FOCUS ON STROKE

Fragmentation of care results in inadequate co-ordination of fundamental components of acute stroke care



4,300

Approximately 4,300 people are admitted to hospital following an acute ischaemic stroke each year



12.3%

On average, 12.3% of patients hospitalised with acute ischaemic stroke receive clot busting therapy (thrombolysis)



4%-5%

Increase

The total number of stroke cases has been predicted to increase by between 4% and 5% each year

PPI – Public and Patient Involvement Stroke Research Priorities

[Int J Stroke](#). 2014 Apr;9(3):313-20. doi: 10.1111/ij.1747-4949.2012.00942.x. Epub 2012 Dec 11.

Top 10 research priorities relating to life after stroke--consensus from stroke survivors, caregivers, and health professionals.

Pollock A¹, St George B, Fenton M, Firkins L.

Author information

Abstract

BACKGROUND: Research resources should address the issues that are most important to people affected by a particular healthcare problem. Systematic identification of stroke survivor, caregiver, and health professional priorities would ensure that scarce research resources are directed to areas that matter most to people affected by stroke.

AIMS: We aimed to identify the top 10 research priorities relating to life after stroke, as agreed by stroke survivors, caregivers, and health professionals.

METHODS: Key stages involved establishing a priority setting partnership; gathering treatment uncertainties from stroke survivors, caregivers, and health professionals relating to life after stroke (using surveys administered by e-mail, post, and at face-to-face meetings); checking submitted treatment uncertainties to ensure that they were clear, unanswered questions about the effects of a treatment/intervention; interim prioritization to identify the highest priority questions (objectively identified from ranking of personal priorities by original survey respondents); and a final consensus meeting to reach agreement on the top 10 research priorities.

RESULTS: We gathered 548 research questions that were refined into 226 unique unanswered treatment uncertainties. Ninety-seven respondents completed the interim prioritization process, objectively identifying 24 shared priority treatment uncertainties. A representative group of 28 stroke survivors, caregivers, and health professionals attended a final meeting, reaching consensus on the top 10 research priorities relating to life after stroke. Six of the agreed top 10 research priorities related to specific stroke-related impairments, including cognition, aphasia, vision, upper limb, mobility, and fatigue. Three related to more social aspects of 'living with stroke' including coming to terms with long-term consequences, confidence, and helping stroke survivors and their families 'cope' with speech problems. One related to the secondary consequences of stroke and subsequent stroke prevention.

CONCLUSIONS: The top 10 research priorities relating to life after stroke have been identified using a rigorous and person-centered approach. These should be used to inform the prioritization and funding of future research relating to life after stroke.

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Stroke patients ‘abandoned’ after hospital discharge

By June Shannon 3rd November 2016

Stroke patients are “effectively abandoned” on discharge from hospital and their opportunities for recovery “needlessly squandered”, the Irish Heart Foundation (IHF) has said.

Launching the IHF/HSE National Stroke Audit of Rehabilitation Units last week, the Foundation’s Head of Advocacy Chris Macey said while lives were being saved on “an unprecedented scale” thanks to advances in acute stroke care such as thrombolysis and thrombectomy, stroke patients were then effectively abandoned on discharge due to a lack of community rehabilitation services.

The IHF/HSE audit of 26 rehabilitation units or hospitals across the country revealed that 73 per cent of units could not provide the recommended level of therapy to patients, 77 per cent had no dedicated stroke unit, 81 per cent had no access to an Early Supported Discharge Team and 61 per cent had no access to a Community Rehabilitation Team.

The audit, which is the first study of post-acute stroke care in Ireland, also found that the majority or 69 per cent of rehabilitation units had no access to psychology services and less than half or 42 per cent of sites had a stroke specialist.

Leaving hospital is ‘like falling off a cliff’ for stroke survivors (Stroke Association UK)

There needs to be a range of evidence-based services available and flexibility for patients to follow a tailored care pathway based on their needs.



Public & Patient Involvement (PPI)



PPI informed research questions for HRB a funded CDA iPASTAR [CDA-2019-004] 2020-2025
Williams D, Horgan F, Hickey A, Sorensen J [RCSI] Lennon O [UCD]

<https://ipastar.eu>



iPASTAR OVERVIEW - PROJECTS

Research Projects & PhD Trainees

PROJECT 1

Maximising accessibility and equity of acute stroke care pathways in Ireland

Dr. Deirdre McCartan
-
Clinician

Training Programme

PROJECT 2

Beyond early supported discharge (ESD): Improving and supporting transitions of care for stroke

Geraldine O'Callaghan
-
Physiotherapist

Mentoring & Career Development

PROJECT 3

Staying well and reducing risk after stroke

Patricia Hall
-
Nurse

Programme Governance/ Management

PROJECT 4

Cost and cost-effectiveness of current stroke care pathways and the developed interventions

Clare Fitzgerald
-
Health Economist

Public & Patient Involvement

Evidence to inform policy & practice in stroke, with a focus on transitions in care, to improve patient outcomes and build research capacity

WHAT WE ARE GOING TO DO?

Improving Pathways for Acute Stroke And Rehabilitation

iPASTAR

Advancing an evidence-based and cost-effective stroke pathway by:

Identifying and addressing current **barriers and facilitators** in the acute stroke pathway

Describing **supports for seamless transitions of care** across the continuum of early supported discharge and rehabilitation

Identifying optimal **behavioral interventions** in secondary prevention to **maintain wellness after stroke** and reduce recurrence

Developing a “**programme budget**” for stroke pathways and **modelling** proposed **pathway changes**



The iPASTAR Cohort

iPASTAR will generate a cohort of **post-doctoral researchers** with **transferrable skills** who can make a significant **future impact** across a range of healthcare settings with the necessary **expertise** to support evidence-based and cost-effective management of stroke in partnership with our PPI advisory group and PPI champions.



iPASTAR

Improving Pathways for Acute Stroke and Rehabilitation



RCSI

The Researcher and PPI journey



• Types of PPI

- Co-Researcher
- Advisory Panels
- Steering Committee representation
- Co-Design Teams
- ‘Town Hall’ Meetings
- Lay reviewer and evaluator
- Expert patient

– Types of study design

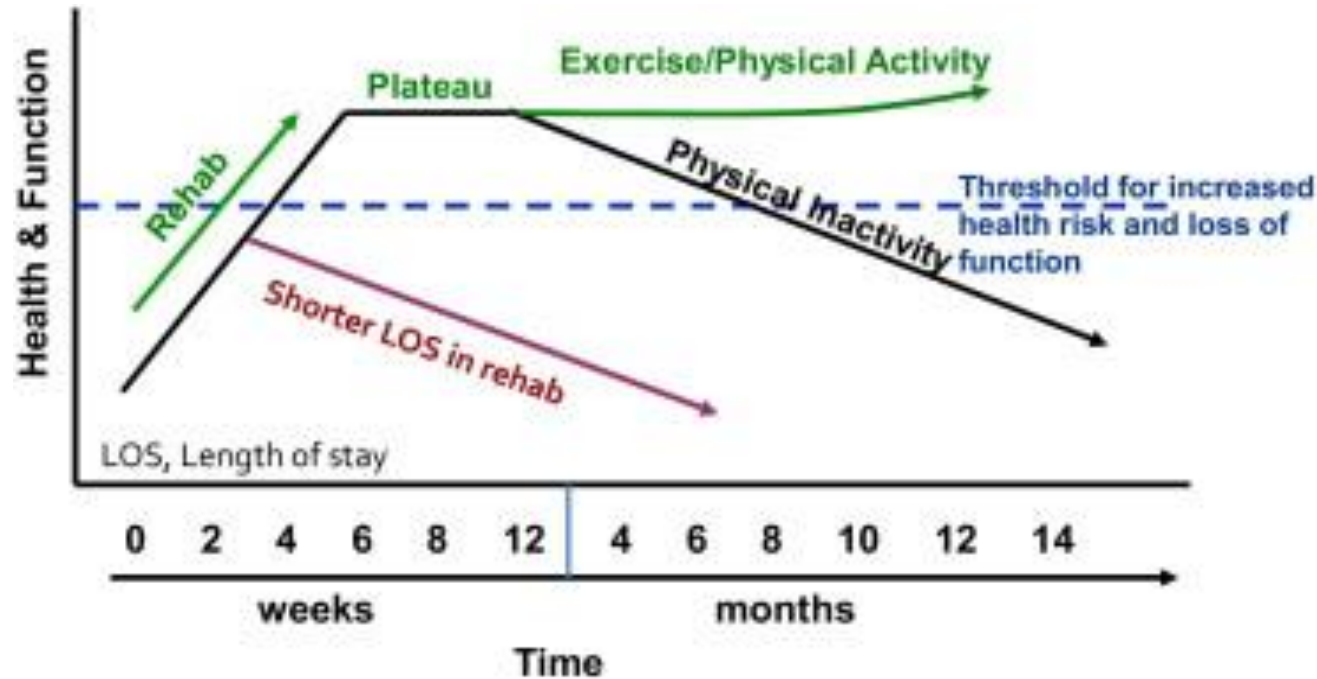
- Systematic review, trial, qualitative, evaluation, implementation, co-design, health economics

Key elements –

- Accessibility
- Flexibility – Diversity
- Inclusivity
- Build relationship/trust
- Think about partner benefits
- Co-create ‘ways of working’
- Power structures
- Managing expectations
- Add time
- Financial considerations
- evaluation



Generating new priorities from PPI discussions..... getting beyond the stroke plateau: bridging the gaps, ageing with stroke



- **Access to community-based rehabilitation and fitness programmes to continue recovery**
 - Reducing the risks of debilitating secondary health conditions
 - Optimising health and function.
 - What is the best way to achieve this? Co-designing solutions together.

Conclusion

- Patients in Ireland have a **key role** to play in
 - **improving** the **quality** of the health service they receive by participating in the design and delivery of the service themselves.
 - **Meaningful consultation** with patients to help providers, clinicians and researchers to understand the quality of care a patient receives.
 - Patient centric research, as we develop evidence of the effectiveness for future treatments and co-design solutions for value based healthcare.

Thank you