



SIP

Societal Impact of Pain

2017

Structured Cooperation
between Health Care
Systems tackling the
societal impact of pain!

The Patient & Client Council

Who We Are

&

What We Do for People in Pain

Louise Skelly

Head of Operations

Our role in Health and Social Care



To provide a **powerful, independent** voice
in health and social care for patients, clients,
carers and communities.



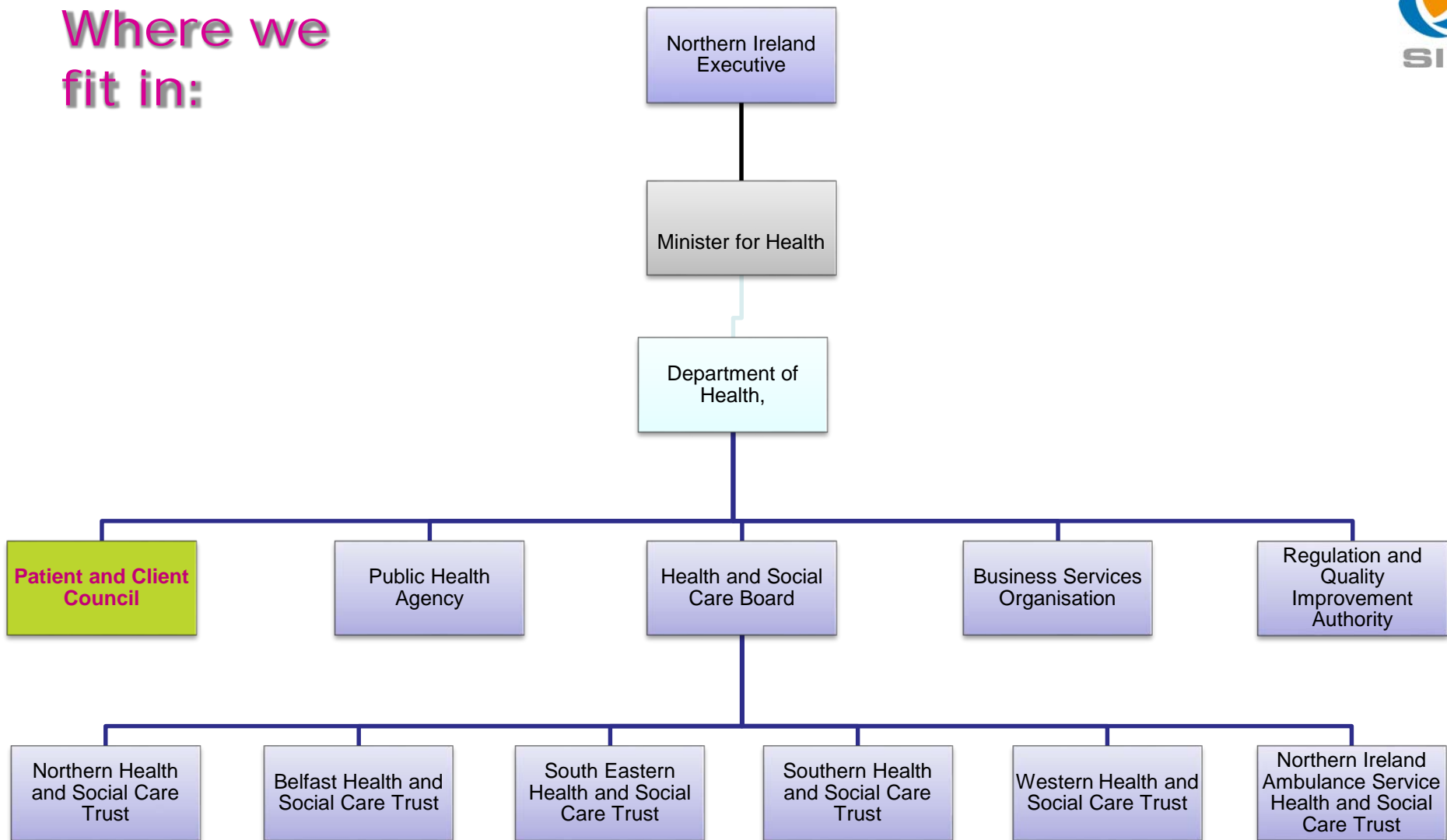
The Patient & Client Council

Statutory Functions



- **Listen** and **act** on people's views.
- **Encourage** people to get involved.
- **Help** people make a complaint.
- **Provide** advice and information.

Where we fit in:



Health and Social Care Environment

- Currently In transition
- Donaldson Report 2015
- Professor Rafael Bengoa - Report
- Minister O'Neill – Systems not Structures
- Commissioning Board (Health and Social Care Board) – 2019
- NI Assembly – Suspended



Strategic Context for Pain

There was currently no co-ordinated approach or strategy for the management of long term pain in NI

Scotland and Wales had published policy documents addressing care pathways and coordinated services for the treatment of pain.

In England, the Chief Medical Officer devoted a separate chapter on pain in his Annual Report for 2008 (published in 2009), thus indicating that pain had become a significant public health issue. A number of working group have been established to take the work on pain forward.



Pain Management Services in NI

- Pain management services are provided by consultant led or nurse led clinics. Gaps & inequalities
- Pain clinics are generally held in hospitals, but are not necessarily local services.
- Pain clinics do not offer the same service across Northern Ireland - acupuncture treatment, injection-based, or surgical interventions
- Heavy reliance on pharmacological treatments
- Health economic benefits of effective and timely pain management not established as for other long term conditions.



The Painful Truth

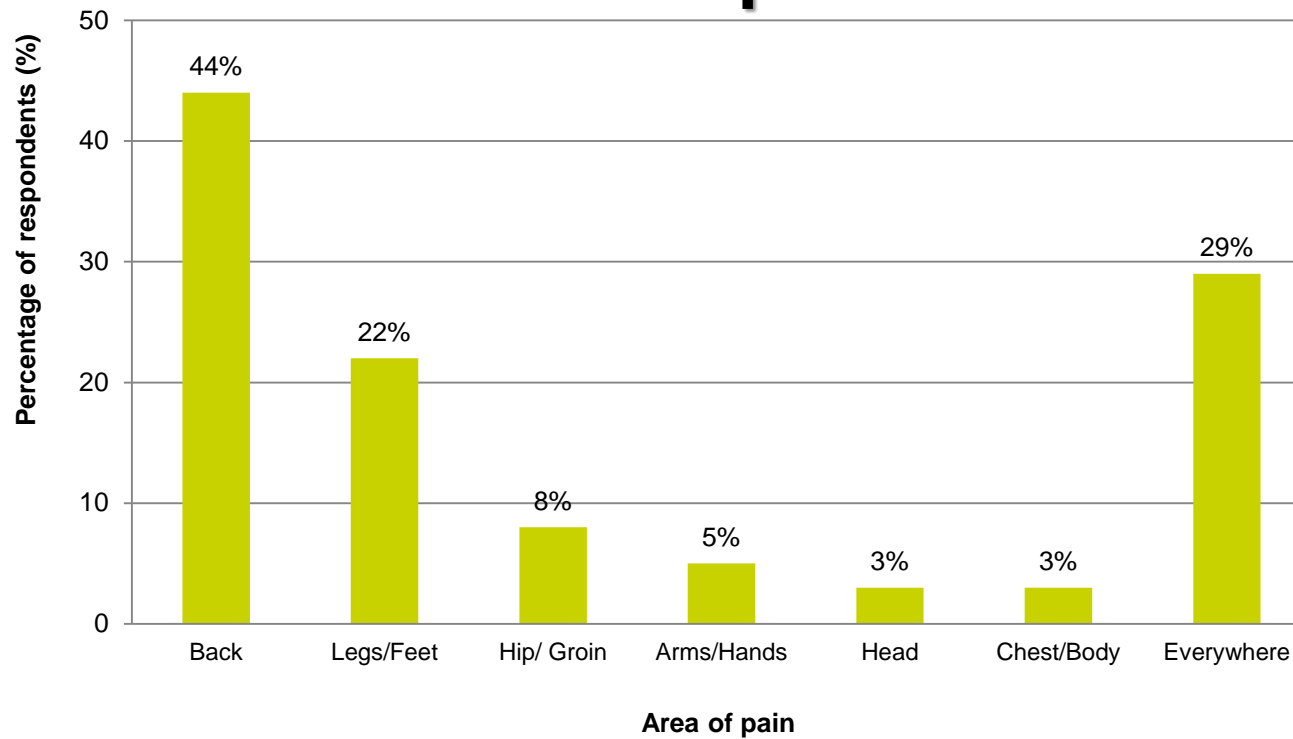
2500 people who live with chronic pain tell their story

- Individual people sought help from PCC
- Isolation / No understanding of their plight
- PCC sought to understand extent of problem
- Major survey – lived experience & experience of health care
- 2,500 people told story
- Report launched in 2014
- Made 10 key recommendations
- 8 were accepted and recommended for implementation by Minister for Health

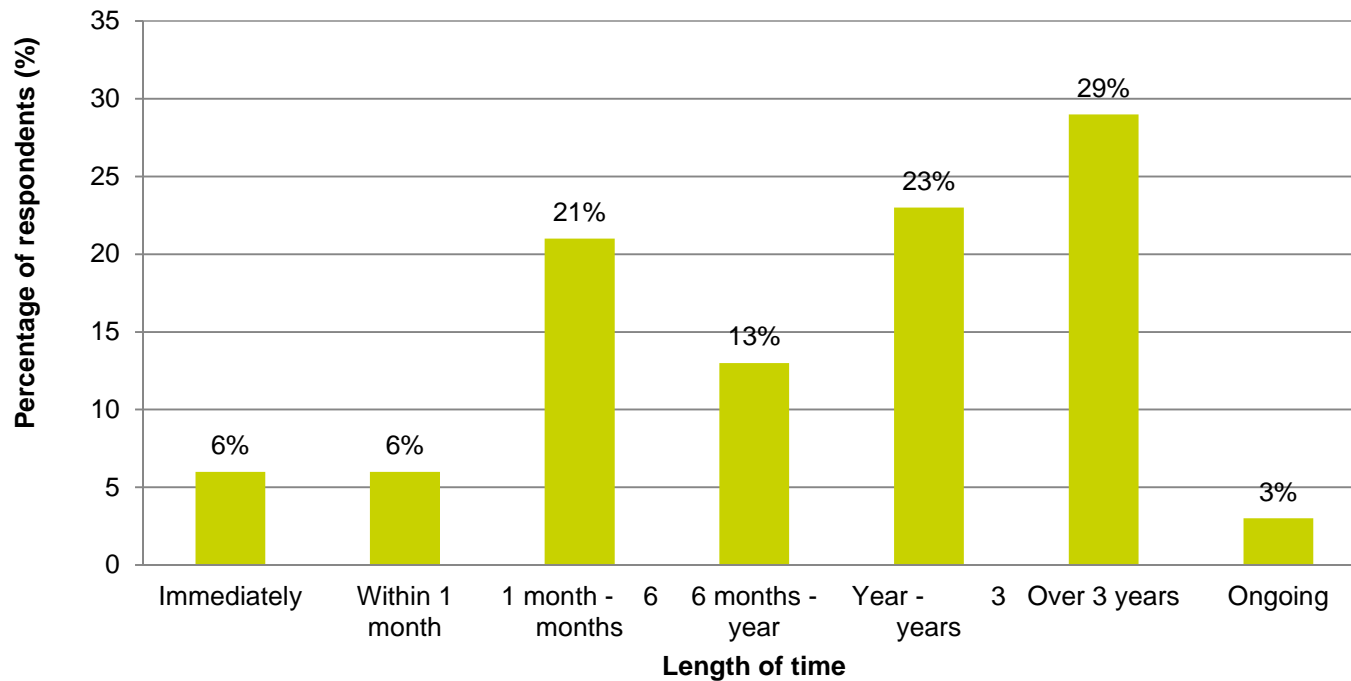


Findings

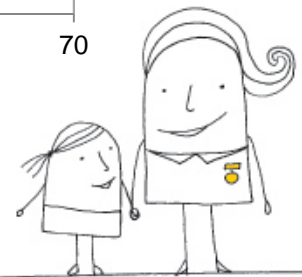
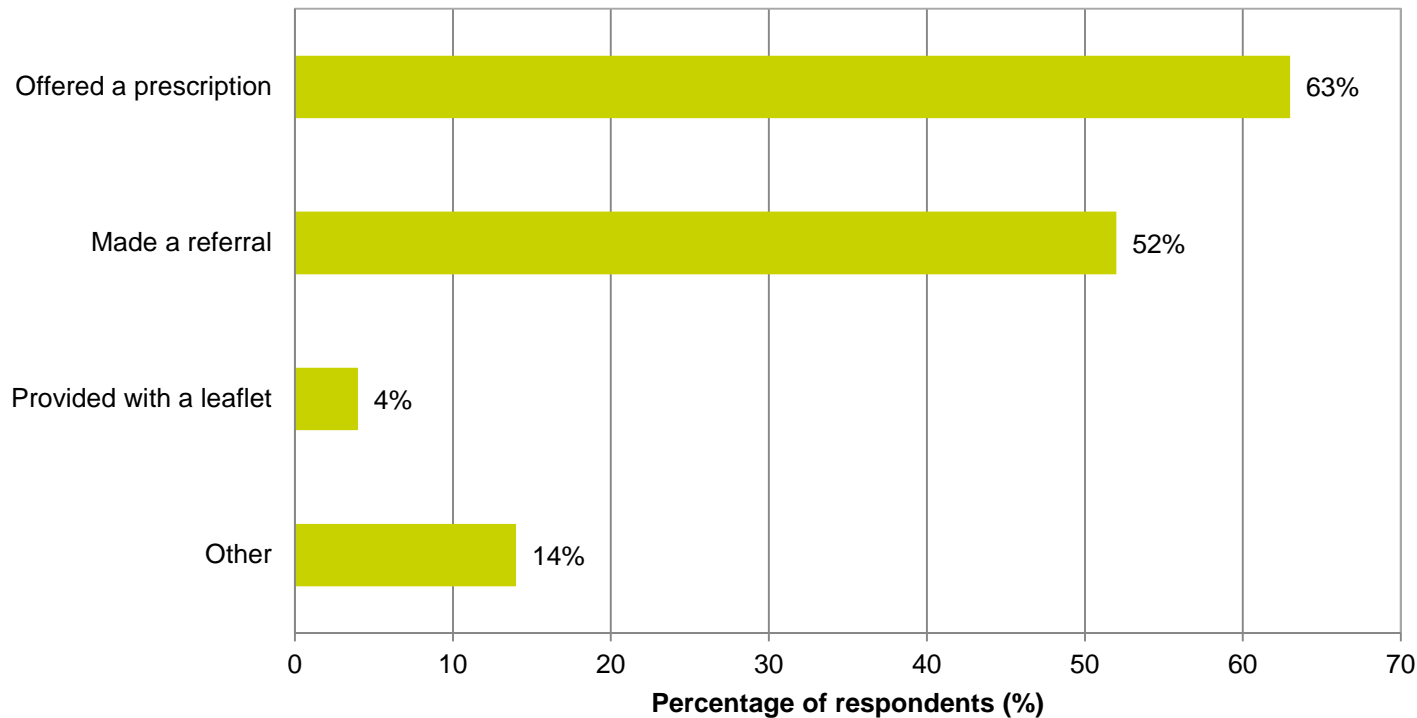
Where people experienced pain



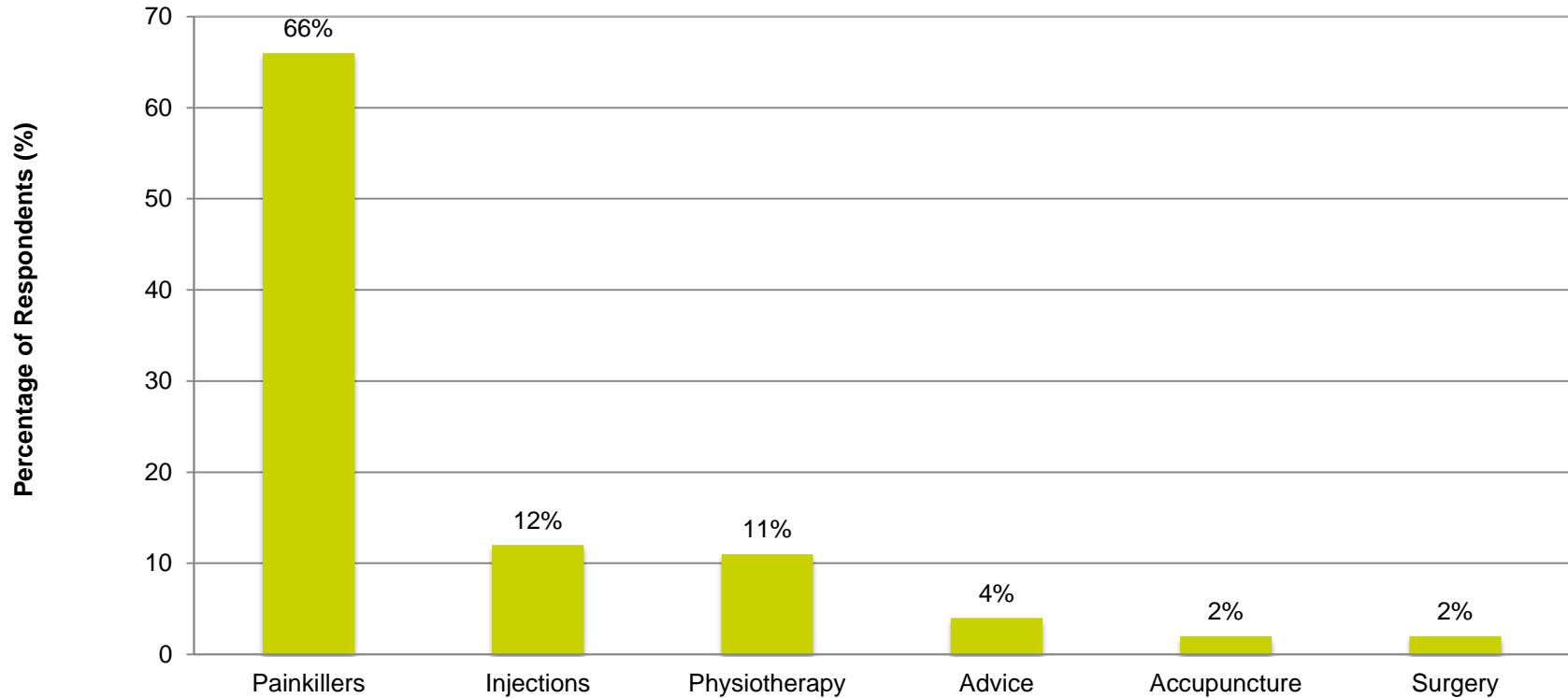
How Long did it take to get a diagnosis?



What action did your GP take when you first saw them about your pain?



What options were given to you to manage your pain?



Options to Manage Pain



What Works for You?

1. **Medication and pain relief**
2. **Support from GPs and other health professionals**
3. **Physiotherapy**
4. **Alternative therapies or treatments**
5. **Pain clinic**
6. **Surgery**
7. **Support groups, family support, charity organisations**
8. **Self-management**



What Does Not Work for You?

- 1. Medication and pain relief**
- 2. Support from health professionals**
- 3. Physiotherapy**
- 4. Waiting time**
- 5. Lack of action, treatment plans, or advice on self-management**
- 6. Getting a diagnosis**



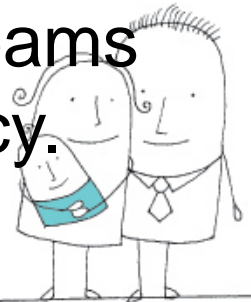
Recommendations

1. Long-term pain should be recognised as a condition in its own right by all HSC organisations who deliver care.
2. Training and/or information leaflets aimed at GPs and front line health care professionals should be developed. The aim of these resources should be to increase awareness and inform health care staff on what long-term pain is and its effects on those who have it.



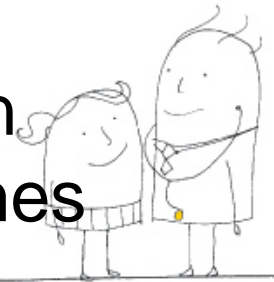
Recommendations

3. Information resources developed for healthcare staff should be directly informed by and content/user tested with those people who live with long-term pain and/or their carers and relatives.
4. A Strategic Framework for Pain Services should be developed. The framework should prioritise local primary care led multi-disciplinary teams and be supported by community pharmacy.



Recommendations

5. Long-term pain management approaches need to be embedded into Integrated Care Partnerships so that those with chronic pain benefit from the delivery of responsive, innovative and multi-disciplinary health care in the future.
6. Service models based on local population needs should be in place across Northern Ireland.
7. Patients should be offered a range of pain management care and support programmes including supported self-management.



Recommendations

8. The role of mainstream alternative therapies should be reviewed specifically for support and help for those people living with long-term pain.
9. An integrated Northern Ireland cross-departmental strategy to manage chronic pain is needed to allow people to manage their pain and to empower them to lead full and active lives.
10. Information resources for patients, clients, carers and their relatives affected by long-term pain should be developed to help people understand, make decisions about and cope with long-term pain.



So What has happened so far

- **8 of 10 recommendations currently being implemented**
- **Long term pain is recognised as a long term condition**
- **Priority in the 2014/15 Commissioning Plan**
- **Recognition at Senior level of pain and surrounding issues**
- **Regional Pain Forum (Patients & Professionals)**



Regional Pain Forum – Some achievements



- **5 Year Specialty Development Plan**
- Pain Management Commissioning Specification for Primary Care
- **Undergraduate Medical Education** – Queens University Belfast – Chronic pain Management reinstated
- **Information** and Signposting Page on NI Direct – in progress
- Fibromyalgia Care Pathway
- Physiotherapists – {Painful Truth Recommended Reading List}
- Training for GPs in supporting Self Management in Pain
- Queens University Belfast – On Line training programme in pain for pharmacists
- Series of ½ day training sessions for GPs on Chronic Pain Management
- University of Ulster – considering enhancing Nurse Education
- Hackathon – Innovation for an APP

Key Learning

- Fundamental Importance of listening to lived experience
- There are still groups of patients whose voice is unheard (chronic pain sufferers, fibromyalgia, women with stage 4 endometriosis, CFS/ME etc.)
- Its take time to effect change
- Don't give up – you need to stick with your vision even in challenging times
- Co-production is fundamental to creative ways of working

Any Questions?

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Within the past 12 months, I or my spouse/partner have had following financial interest/arrangement(s) or affiliation(s)

- **Support for travel**None.....
- **Honoraria for lectures**Nil.....
- **Honoraria for advisory board activities**Nil.....
- **Participation in clinical trials**Nil.....
- **Research funding**Nil.....
- **Financial shares and options**Nil.....
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