THE PAINFUL TRUTH.

Louise Skelly
Patient and Client Council
The Painful Truth

Providing a voice for chronic pain sufferers – our journey so far

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:

Northern Ireland Executive

Minister for Health

Department of Health,

Patient and Client Council

Northern Health and Social Care Trust

Public Health Agency

Belfast Health and Social Care Trust

Health and Social Care Board

South Eastern Health and Social Care Trust

Business Services Organisation

Southern Health and Social Care Trust

Western Health and Social Care Trust

Regulation and Quality Improvement Authority

Northern Ireland Ambulance Service Health and Social Care Trust
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

- **44%** Back
- **22%** Legs/Feet
- **8%** Hip/Groin
- **5%** Arms/Hands
- **3%** Head
- **3%** Chest/Body
- **29%** Everywhere

Where people experienced pain

**Percentage of respondents (%)**
- 0
- 10
- 20
- 30
- 40
- 50
How Long did it take to get a diagnosis?

- Immediately: 6%
- Within 1 month: 6%
- 1 month - 6 months: 21%
- 6 months - year: 13%
- Year - 3 years: 23%
- Over 3 years: 29%
- Ongoing: 3%
What action did your GP take when you first saw them about your pain?

- Offered a prescription: 63%
- Made a referral: 52%
- Provided with a leaflet: 4%
- Other: 14%

Percentage of respondents (%)

0 10 20 30 40 50 60 70
What options were given to you to manage your pain?

Options to Manage Pain

- Painkillers: 66%
- Injections: 12%
- Physiotherapy: 11%
- Advice: 4%
- Acupuncture: 2%
- Surgery: 2%
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.
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 Commissioning Plan
• Recognition at Senior level of pain and surrounding issues
• Regional Pain Forum (Patients & Professionals)
• Co Production
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 pharamacists
• Series of $1/2$ day training sessions for GPs on Chronic Pain Management
• University of Ulster – considering enhancing Nurse Education
• Hackathon – Innovation for an APP
GLOBAL DIGITAL SNAPSHOT
THE LATEST NUMBERS FOR INTERNET, SOCIAL MEDIA, AND MOBILE USAGE AROUND THE WORLD

TOTAL POPULATION: 7.524 BILLION
URBANISATION: 54%

INTERNET USERS: 3.819 BILLION
PENETRATION: 51%

ACTIVE SOCIAL MEDIA USERS: 3.028 BILLION
PENETRATION: 40%

UNIQUE MOBILE USERS: 5.052 BILLION
PENETRATION: 67%

ACTIVE MOBILE SOCIAL USERS: 2.780 BILLION
PENETRATION: 37%

SOURCES:
- POPULATION: UNITED NATIONS; U.S. CENSUS BUREAU; INTERNET; INTERNETWORLDSTATS; ITU; INTERNETUSERSTATS; CIA WORLD FACTBOOK; FACEBOOK;
- NATIONAL REGULATORY AUTHORITIES;
- SOCIAL MEDIA AND MOBILE SOCIAL MEDIA: FACEBOOK; TENCENT; VKONTAKTE; LIVEINTERNET.RU; KAKAO; NAVER; NIKI;
- AGHAEI; CAFEBAZAAR;IR; SIMILARWEB; DINO; EXTRAPOLATION OF TNS DATA;
- MOBILE: GSMA INTELLIGENCE; EXTRAPOLATION OF EMARKETER AND ERICSSON DATA.
Information and services

**Motoring**
MOT and vehicle testing, vehicle tax and registration, driver licensing, learner drivers, driving for a living, road safety
[more](#)

**Money, tax and benefits**
Information on tax, benefits, welfare changes, pensions, money abroad, managing money and debt
[more](#)

**Pensions and retirement planning**
Information and guidance about planning for retirement including forecasting your pension, how much income you will have and when to retire
[more](#)

**Government, citizens and rights**

**Parents**

**Employment**
Employment terms and conditions, redundancy, leaving your job, health and safety at work, workplace disputes and looking for work
[more](#)

**Travel, transport and roads**
Public transport, air travel, parking, bus lanes and how to report problems with a road or street
[more](#)

**People with disabilities**
Information for people with disabilities on topics including employment, financial support, accessibility and rights
[more](#)

Popular information
- Universal Credit
- AccessNI criminal record checks
- Check your State Pension age
- Book, change or cancel an MOT/vehicle test appointment
- Holiday entitlements

Popular services
- Book an MOT/vehicle test online
- Apply online for an enhanced check through a registered body
- Book, change or cancel your theory test online
- Book your practical driving test online
My Health

How Healthy Are You Really?

https://www.myni.life/
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.)

• It's 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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NUFFIELD HALL
NHS Improvement and the Well-led framework - putting good engagement into practice – Kiran Chauhan & Ashfa Slater, NHS Improvement

COUNCIL CHAMBER
Public Engagement: Mission Possible – Elouise Smith and team, MES

COMMITTEE ROOM 1
Cancer, to Patient Partnership and Beyond – Sara Turle, Barking, Havering and Redbridge University Hospitals NHS Trust