EXPLORING PUBLIC & PATIENT PARTICIPATION TO GUIDE RESEARCH IN WOUND CARE IN AN IRISH CONTEXT

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Background

• The Alliance for Research and Innovations in Wounds (ARIW) was founded in 2017 to further develop and expand wound care in Ireland and Internationally.

• ARIW brings together expertise in research, education and clinical practice that exists within NUI Galway, Saolta and private healthcare partners.

• ARIW’s vision is:
  “To address the challenges for everyone affected by wounds through collaboration, pioneering research and innovation”

• ARIW conducted an open public event in October 2017 to identify patient and carer research priorities.
Methods

• Roundtable discussion format at an open public event
• Format guided by ‘The Participation Toolkit (2014)’ developed by the Scottish Health Council
• Each roundtable was facilitated by 2 ARIW Team members
• Detailed written field notes and audio recordings of discussions taken
RoundTable Report

• Participants included patients, carers, clinicians and non-clinical academics (N=36)

• Data was analysed using Inductive Thematic Analysis

• The Guidance for Reporting Involvement of Patients and the Public 2 – Short Form (GRIPP2-SF) guided the reporting process

  (Staniszewska et al 2017)
Themes Identified

5 main themes identified with associated subthemes

1. Impact of wound
2. Pain management
3. Wound management
4. Financial & Practical Burden
5. Educational Needs
1. Impact of Wound

Subthemes

• Quality of Life
  • Long term condition – 30%
  • Social restriction/ Loss of independence

• Patient Priorities
  • Access to care
  • Need for education
  • Protection of wound - Ongoing vigilance
RoundTable Report

2. Pain Management

- Ongoing burden of pain
- Impact of both chronic and acute pain

“Very little helps when the pain is bad” (Patient 1)
3. Wound Management

Subthemes

- Sensitivity/Allergy/Itch/Exudate
  - The importance of self care and access to services for wound care
  - Exudate problematic and embarrassing
  - Carers would like to know how to tackle the cause of exudate so management of this could be improved.

“Affects everything, clothes, walking, footwear” (Patient 2)
3. Wound Management

Subthemes

• Dressing & Bandages
  • Different styles of bandaging & dressing types irritating
    “Some effective but others can do more harm than good” (Patient 3)
  • Lack of staff resources undermines good work
  • Staff changes and ‘Trial and error approach’ viewed as potentially setting wound care back
3. Wound Management
Subthemes
• Continuity of Care
  • Lack of staff resources undermines good work
  • Patients should be viewed as the expert in respect of their wound
  • Lack of continuity between hospital and community

“You would not want a different hairdresser so why have a different nurse do your wound week to week”. (Patient 4)
RoundTable Report

3. Wound Management

Subthemes

• The Professionals view of deterioration
  • Lack of adherence to prescribed footwear, wound care and self bandaging
  • Staff critical of patients using inappropriate products and not responding to advice
RoundTable Report

4. Financial Burden

• Serious burden

• A drain on personal finances

• County to county differences in entitlements
5. Educational Needs

Subthemes

• Professional Perspective
  • Patients can’t/won’t take responsibility for wound healing
    “We as clinicians need to encourage more ownership of wound healing by patients” (Clinician 1)
  • Public Health Nurses (PHN) Lack of resources, dressings, supplies and time.
  • Lack of wound care knowledge in hospital services and continuity of care
    “Everyone does it (wound care) different” (Clinician 2)
5. Educational Needs

Subthemes

• Patient Perspective
  • A view that the patient should educate the nurse
  • A lack of collaboration/ listening to patients
  • A lack of support and education
  • The need for support groups expressed

“Nurses give a cold reaction when you try to educate them” (Patient 5)
“Learn as we go along” (people with wounds)
(Carer 1)
Patients and Carers Recommendations for future research:

- Dressing & Bandages – more research needed
- Wound Care Educational Support Strategies & Resources
  - For both Professional and Patient Education
    - Support Groups/ Leg Ulcer Clubs
    - Suggestion of DVD to educate both patients and family members as
      “Families don’t understand burden” (Patient 2)
      “Might have stopped it progressing” (Patient 1)
RoundTable Report

Future Directions

• Participant evaluation

• Participants expressed a strong interest in further wound care Public & Patient Involvement (PPI) events

• ARIW plans an additional event for October 2018
Thank you
References

