



NUI Galway
OÉ Gaillimh

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

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A Roundtable Report

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



RoundTable Report

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)



RoundTable Report

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)



RoundTable Report

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



RoundTable Report

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



RoundTable Report

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)



RoundTable Report

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)



RoundTable Report

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





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Alliance for Research and
Innovation in Wounds

Thank you

References

- Scottish Health Council (2014) *The Participation Toolkit: Supporting Patient Focus and Public Involvement in NHS Scotland*. Healthcare Improvement, Scotland 2014.
- Staniszewska, S., Brett, J., Simera, I., Seers, K., Mockford, C., Goodlad, S., Altman, D.G., Moher, D., Barber, R., Denegri, S. and Entwistle, A., (2017). GRIPP 2 reporting checklists: tools to improve reporting of patient and public involvement in research. *Research involvement and engagement*, 3(1), p.13.
- Staniszewska, S. and Denegri, S., (2013). Patient and public involvement in research: future challenges. *Evidence-Based Nursing* 2013;16:69.