Incorporating Qualitative Evidence in Clinical Practice Guidelines: A Scottish Perspective

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Presentation Overview

• Qualitative research in evidence-based guidelines
• SIGN methodology
• Methods used to incorporate non-traditional evidence
• Limitations encountered
• Suggestions for future work
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SIGN: Scottish Intercollegiate Guidelines Network
Sarah Florida-James, Programme Manager
Guideline Development Sub-Group:
– Celia Brand, Nurse Specialist
– Alix Rolfe, GP
– Chris Jeans, Lay representative
– Aileen McCafferty, Psychologist

Healthcare Improvement Scotland
SIGN

[Map of Scotland with Aberdeen highlighted, pictures of waterfront and university campus]
Qualitative research in evidence-based guidelines

- Qualitative research increasingly used in guideline development
- Lewin & Glenton (2018) “entering a new era for qualitative research”
- Use of qualitative approaches:
  - NICE (UK)
  - Social Care Institute for Excellence (UK)
  - World Health Organization
  - South African Fetal Alcohol Spectrum Disorders Task Team

Qualitative research in evidence-based guidelines

• Address questions of:
  – Acceptability
  – Feasibility
  – Perspectives of service users & carers
  – Processes
  – Implementation

Qualitative research in evidence-based guidelines

- Enhanced methods in recent years
- Reporting standards
- Evidence synthesis methodology
- Enhanced indexing
- Assessment of confidence in findings (GRADE CERQual & JBI ConQual)
- Evidence to decision frameworks

Lewin & Glenton (2018)
SIGN Methodology

1. **Topic selection**
   - Informed by stakeholder consultation

2. **Systematic literature review for each Key Question (PICO)**
   - Evidence tables produced & methodological quality assessed

3. **Considered Judgement**
   - Quality of evidence & factors affecting strength of recommendation
     - Risk of bias/Heterogeneity/Directness/Precision/Publication bias

4. **Making Recommendations**
   - Research evidence + clinical expertise + patient values
   - Consensus on Strong or Conditional recommendations +/- Good Practice Points

SIGN Methodology

5. Consultation & Peer-review
   - National Open Meeting/Invited Peer Review/SIGN Website

6. Presentation & Publication

7. Implementation
Epilepsies in Children & Young People: Investigative Procedures & Management

• Guideline Development Group
  – Clinicians (Neurologists, Paediatricians, Radiologist, Geneticists, Pharmacist, Nurse specialist, Dietician, Clinical Psychologist, GP)
  – SIGN staff (Programme manager, Health economist, Information scientist,
  – Lay & voluntary body representatives (Young people, parents/carers, Scottish Paediatric Epilepsy Network, Epilepsy Scotland)
Epilepsies in Children & Young People: Investigative Procedures & Management

Need identified: Last Guideline 2005

“Non-traditional research evidence”

11 Key Questions Developed

Literature review conducted
“Non-traditional” research evidence

• 2 Key Questions returned majority descriptive, qualitative & text/opinion

• At what age and by what process do children/adolescents with epilepsy best transition from paediatric to adult care?

• When should children and young people and parents/carers be told about the possibility of SUDEP/mortality?

• Not possible to answer Key Questions...
At what age and by what process do children/adolescents with epilepsy best transition from paediatric to adult care?

Modified PICO:
Patients’, family members/carers & clinicians views of transition

- Systematic Review (neurology), Scoping reviews, Mixed-methods reviews, Cross-sectional studies & Text/opinion

- JBI Critical Appraisal Tools (where possible)

- 1 Conditional Recommendation
- 2 Good Practice Points
When should children and young people and parents/carers be told about the possibility of SUDEP/mortality?

Modified PICo: When, where and how should discussions about SUDEP take place?

Novel mixed-methods evidence synthesis initiated (5 cross-sectional, 4 qualitative, 1 opinion) + additional qualitative & mixed-methods primary research

JBI Critical Appraisal Tools
JBI ConQual: Dependability & Credibility

1 Conditional Recommendation (Draft Guideline)
Mixed-methods review (Pending)
Conclusion

Unable to address key questions

2 Conditional recommendations & 2 Good practice points (to date)
Limitations

• Clinicians less familiar with literature types
  – Impact on Considered Judgement Process
• Evolution of process over time
  – Need to plan for inclusion of qualitative evidence from outset
  – Need to allow adequate time for novel evidence syntheses
• Lack of critical appraisal tools for some types of evidence
• Interpretability?
• Implementation?
Future Work

- Critical appraisal tools
- GRADE CerQual
- Review of SIGN 50: Guideline Developer’s Handbook
References & Reading


References & Reading


• Tan TPY, Stokes T, Shaw EJ. Use of qualitative research as evidence in the clinical guideline program of the National Institute for Health and Clinical Excellence. Int J Evid Based Healthc 2009; 7: 169-172.
Thank you for listening!

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