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







Scottish JBI Centre

Robert Gordon University Kay Cooper, Allied Health Professions Pamela Kirkpatrick, Nursing



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





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

Tan et al (2009); Lewin & Glenton (2018); Coombs et al (2017)







Qualitative research in evidence-based guidelines

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

Tan et al (2009); Lewin & Glenton (2018); Coombs et al (2017)







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

- Topic selection
- Informed by stakeholder consultation
- Systematic literature review for each Key Question (PICO)
- Evidence tables produced & methodological quality assessed
- Considered Judgement
 - Quality of evidence & factors affecting strength of recommendation
 - Risk of bias/Heterogeneity/Directness/Precision/Publication bias
- Making Recommendations
- Research evidence + clinical expertise + patient values
- Consensus on Strong or Conditional recommendations +/- Good Practice Points

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SIGN Methodology

 Consultation & Peer-review National Open Meeting/Invited Peer Review/SIGN Website Presentation & Publication 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



11 Key Questions
Developed



"Non-traditional research evidence"



Literature review conducted





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"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?



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







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Thank you for listening!

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