PREGNANCY LOSS RESEARCH GROUP

Developing guideline-based indicators for recurrent miscarriage care with a diverse stakeholder group

Marita Hennessy[1-3], Laura Linehan[1-3], Rebecca Dennehy[1-3], Declan Devane[2,4,5], Rachel Rice[1,6], Sarah Meaney[7], Keelin O'Donoghue[1-3]

[1]Pregnancy Loss Research Group, Department of Obstetrics and Gynaecology, University College Cork, Cork, T12 DC4A, Ireland; [2]INFANT Research Centre, University College Cork, Cork, T12 DC4A, Ireland; [3]College of Medicine and Health, University College Cork, Cork, T12 EKDO, Ireland; [4]School of Nursing and Midwifery, National University of Ireland, Galway, Galway, H91 E3YV, Ireland 5 Evidence Synthesis Ireland, National University of Ireland, Galway, Galway, H91 E3YV, Ireland; [6]School of Applied Social Studies, University College Cork, Cork, T12 D726, Ireland; [7]National Perinatal Epidemiology Centre, University College Cork, Cork, T12 DC4A, Ireland

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BACKGROUND

- Standardised care pathways tailored to women/couples who experience RM are needed; ; however, clinical practice can be inconsistent and poorly organised
- No clinical guideline for RM care in Ireland, nor has the provision of RM services within all 19 maternity units/hospitals been examined
- **Lack of patient involvement** in guideline-based key performance indicator (KPI) development and guideline development

OBJECTIVES

1. **Develop and agree a suite of guideline-based KPIs** to measure recurrent miscarriage care quality
2. **Investigate how can a diverse stakeholder group—including health professionals, decision-makers and women and men with lived experience—could be involved in such processes.** The need for greater stakeholder involvement has been highlighted as similar exercises have tended to involve clinicians only

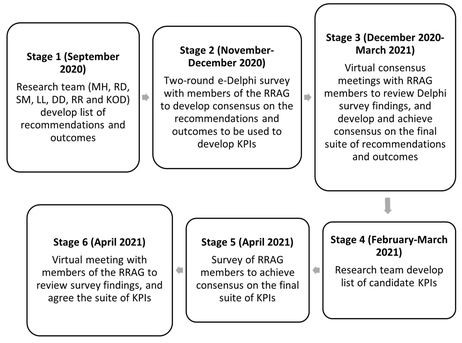
METHODS

Modified e-Delphi study with members of the RE:CURRENT (Recurrent miscarriage: Evaluating current services) Research Advisory Group (RRAG)

In line with the Guidelines International Network Performance Measures Working Group reporting **standards for guideline-based performance measure development** and re-evaluation

Sought feedback from stakeholders on the development process using participatory methods

RE:CURRENT Research Advisory Group comprises 22 individuals with **clinical, methodological and lived experience**: healthcare and allied health professionals, representatives from advocacy and support organisations, those involved in the administration, governance and management of maternity services, academics, and women and men who have experienced RM – in Ireland



RESULTS

Stage 1: Development of a list of recommendations and outcomes from which KPIs could be generated

Recommendations identified from 32 clinical practice guidelines during systematic review (n = 373)

Outcomes identified (n = 14)

Total number of recommendations/outcomes identified by study team (n = 387)

Number of recommendations/outcomes remaining after duplicates removed by study team **(n=201)**

186 recommendations removed

Stage 2: Development of consensus on the recommendations and outcomes to be included in the development of a final suite of KPIs for recurrent miscarriage care – e-Delphi surveys

Number of recommendations/outcomes presented = 201; all brought forward

- Structure of care: 18
- Counselling/supportive care: 13
- Investigations: 76
- Treatment: 80
- Outcomes: 14

Stage 3: Development of consensus on the recommendations and outcomes to be included in the development of a final suite of KPIs for recurrent miscarriage care – consensus meetings

Number of recommendations/outcomes presented = 201 + 3; 113 retained + 4 suggested

- Structure of care (18 - 1[a]): 17 - 0 => 17 retained
- Counselling/supportive care: 13 - 3 => 10 retained
- Investigations (76 + 1[b] - 13[c] - 16[d]): 48 - 8 - 5 => 24 + 11 = 35 retained
- Treatment (80 - 39[e] - 3[f] - 1[g]): 37 - 2 - 1 => 17 + 17 = 34 retained
- Outcomes (14 + 3[h]): 17 => 17 retained, PLUS 4 additional outcomes/KPIs suggested

91 recommendations removed:

67 duplicates removed pre-voting

5 fertility-specific recommendations removed (1-Ix; 4-Tx) pre-voting

19 not rated as important to include

Stage 4: Translation of recommendations into candidate KPIs

Number of recommendations/outcomes to be translated = 117; 117 KPIs generated

- Structure of care (17 + 7[i] + 2[j] – 6[k]) => 20 KPIs
- Counselling/supportive care (10 – 3[k]) => 7 KPIs
- Investigations (35 + 2[j] – 2[k]) => 35 KPIs
- Treatment (34 + 1[b] + 1[j]) => 36 KPIs
- Outcomes (17 + 2[l]) => 19 outcomes

Stage 5: Achieving consensus on the final suite of KPIs – survey

Number of KPIs assessed = 117; 110 retained

- Structure of care: 20 => 20 (100%)
- Counselling/supportive care: 7 => 7 (100%)
- Investigations: 35 => 30 (86%)
- Treatment: 36 => 34 (94%)
- Outcomes: 19 => 19 (100%)

7 KPIs removed; not rated as important to include

Stage 6: Meeting to agree the final suite of KPIs

Number of KPIs included in final suite = 110

Themes generated from responses to "what worked well" and "what could be done differently"

THEME 1:
Richness in diversity

THEME 2:
Accessibility

Sub-themes: Skilled facilitation, communication with/from the research team, virtual access/timing of meetings, making the process more user-friendly

THEME 3
Streamlining the development process

Research Involvement and Engagement

RESEARCH ARTICLE Open Access

Developing guideline-based key performance indicators for recurrent miscarriage care: lessons from a multi-stage consensus process with a diverse stakeholder group

Abstract

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CONCLUSION

From an initial list of 373 recommendations and 14 outcomes, 110 KPIs across five categories, were prioritised for inclusion in a suite of guideline-based KPIs for RM care

It is important, and feasible, to develop guideline-based KPIs with a diverse stakeholder group, including those with lived experience

Insights into our process experiences may help others undertaking similar projects, particularly those undertaken in the absence of a clinical guideline, and/or which involve a range of stakeholders

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