Integrated Participant Digital Storytelling (IPDS): an innovative method for disseminating complex participant stories

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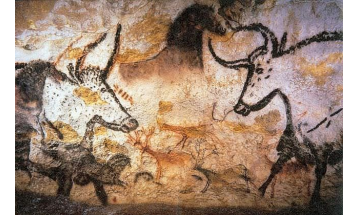[1]University of Bristol, [2]University of Southampton

Background

- Trial findings ➡ Meaningful impact

- Study results and conclusions need to be effectively shared in an engaging and accessible way.

- Requires methods that can
  - captures the thoughts, experiences, and needs of study participants
  - illustrates the nuances and complexity of their journeys in a meaningful and diverse way

Integrated Participant Digital Storytelling (IPDS)
explores and conveys the journeys of multiple participants in an integrated and streamlined manner.

Integrated Participant Digital Storytelling (IPDS)

- **Digital Stories**
  - Storytelling is the oldest form of education – original format was cave paintings (visual)
  - Combining stories from personal experiences with multi-media tools
  - Efficient and effective tool for reaching wider audiences

- **Integrated Participant Digital Storytelling**
  - Applies oral storytelling techniques to qualitative data
  - Multiple people's stories are integrated into one journey
  - Characters are grounded in participants
  - Dialogue is derived from participant accounts

➤ Output based on a constructed person telling their story using multi-media tools such as graphics, audio-recordings or video

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5 stages of IPDS

1
- **Understanding the story**
  - Collecting, understanding and interpreting the qualitative data
  - Determining key experiences through theme development

2
- **Creating the Storyteller**
  - involves drawing on study participant characteristics
    - e.g. gender, roles, ethnicity, age

3
- **Shaping the narrative**
  - Beginning, middle and end
  - Draws on key points in the data

4
- **Producing the story**
  - Storyboarding and script writing using anonymised participant quotations

5
- **Reviewing the story**
  - sharing, revising, and finalising the product of stage 4 with team members.

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Case 1 - Research on Surgeon Engagement in Trials (ReSurgEnT)

AIM

- to understand the role of TRCs and develop strategies to enhance trainee engagement in clinical trials in a mixed methods study.

Data Collection

- 32 interviews were conducted with people from 12 TRCs including trainee surgeons, 7 Clinical Trials Unit (CTU) methodologists, 5 consultant surgeons and 3 research nurses
- A stakeholder workshop with 13 methodologists, surgical trainees, consultants, and research nurses

Key output

- 5 strategies to enhance TRCs were developed through the workshop.

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Using IPDS

- Produced a 6 minute animated video
- Outlined 5 strategies through participants voices and experiences
- represented by the 'Storytellers'

Hello, I'm Louise, trial portfolio coordinator at a Clinical Trials Unit.

Hi, I'm Sam. Joining a trainee collaborative really helped me to build my experience.

- The digital story was shared internationally via
- YouTube - 360 views
- Twitter – 232 tweets
- Uploaded 7 collaborative websites

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Case 2 – Developing an Online Massive Open Online Course (MOOC)

AIM

- To present the evidence about digital tools for improving RCT recruitment and retention in an online training package to increase their uptake and the evidence base
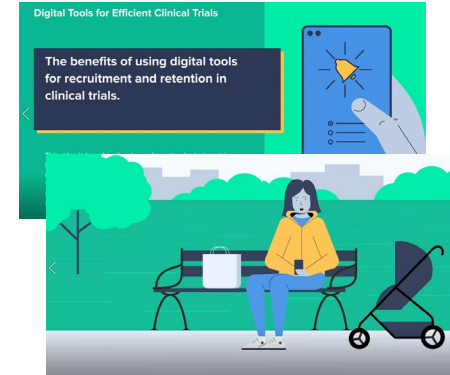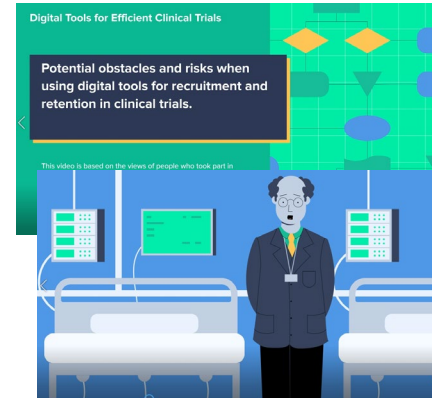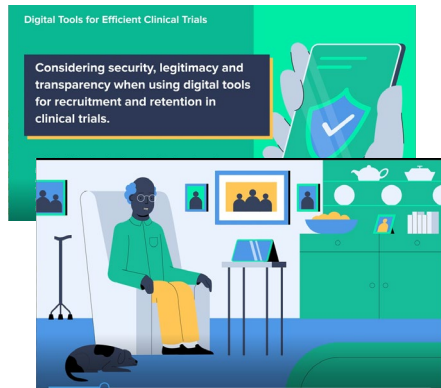
Data used for IPDS

- 16 qualitative interviews were conducted across 5 stakeholder groups (CTU trialists, researchers, funding bodies, ethics committee members and health research authorities and research participants and patient and public representatives)

Key findings from qualitative study

- 5 themes (Security and transparency, Inclusivity and engagement, Human interaction, Obstacles and Risks and Potential benefits)

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- Using IPDS
  - Produced 4 animated digital stories (2-3 mins each)
  - Integrated throughout the MOOC modules
  - Aimed to infuse 'human' views and experiences into the training to help engage trainees
  - Conveyed 5 themes – storytellers grounded in participants/narrative in their stories

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Conclusion

Using IPDS allows sharing of complex participant stories in an accessible and engaging manner and preserves participant stories in their own words.

IPDS can draw the attention of stakeholders and enhance visibility and comprehension of study findings.

Those conducting qualitative research in trials should consider using IPDS to enhance meaningful impact of findings.

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Acknowledgements

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