https://www.facebook.com/EUROlinkCAT/

ConnectEpeople: A social-media-based study exploring research priorities of children with Down Syndrome, Cleft Lip with or without cleft Palate, Congenital Heart Defects and Spina Bifida

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Background to ConnectEpeople

- EUROlinkCAT Establishing a linked European Cohort of Children with Congenital Anomalies

- Horizon 2020 funded project

- ConnectEpeople is Work Package 7

https://www.eurolinkcat.eu/wp7-connectepeople

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ConnectEpeople Project Aims

- Build a online forum called **ConnectEpeople** based in social media
- Connect online with parents of children with a congenital anomaly (CA) in 9 European countries
- Establish an online group of Research Aware Parents (RAPs)
- Work in co-production with RAPs to:
    - Identify and prioritise research questions
    - Investigate communication preferences

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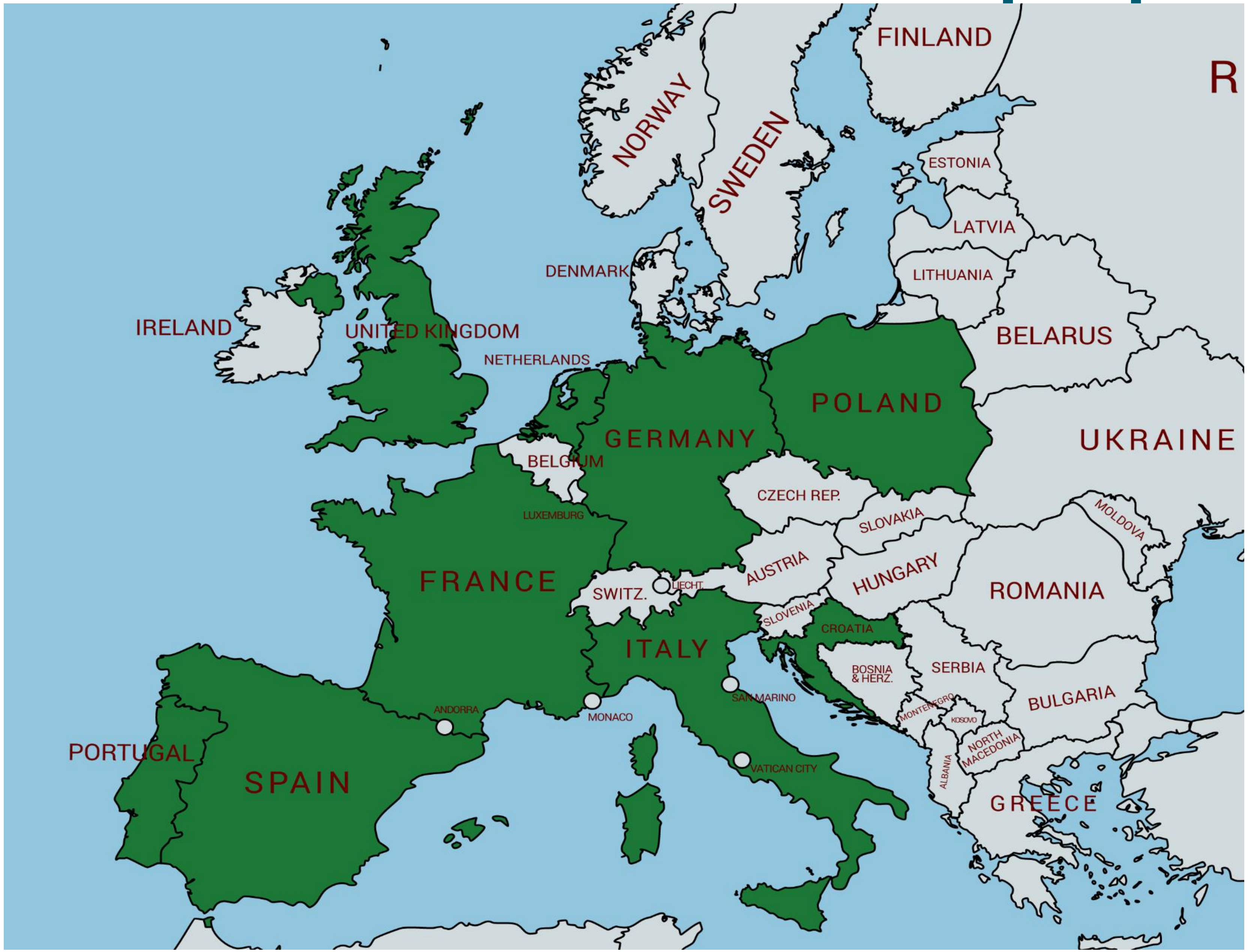
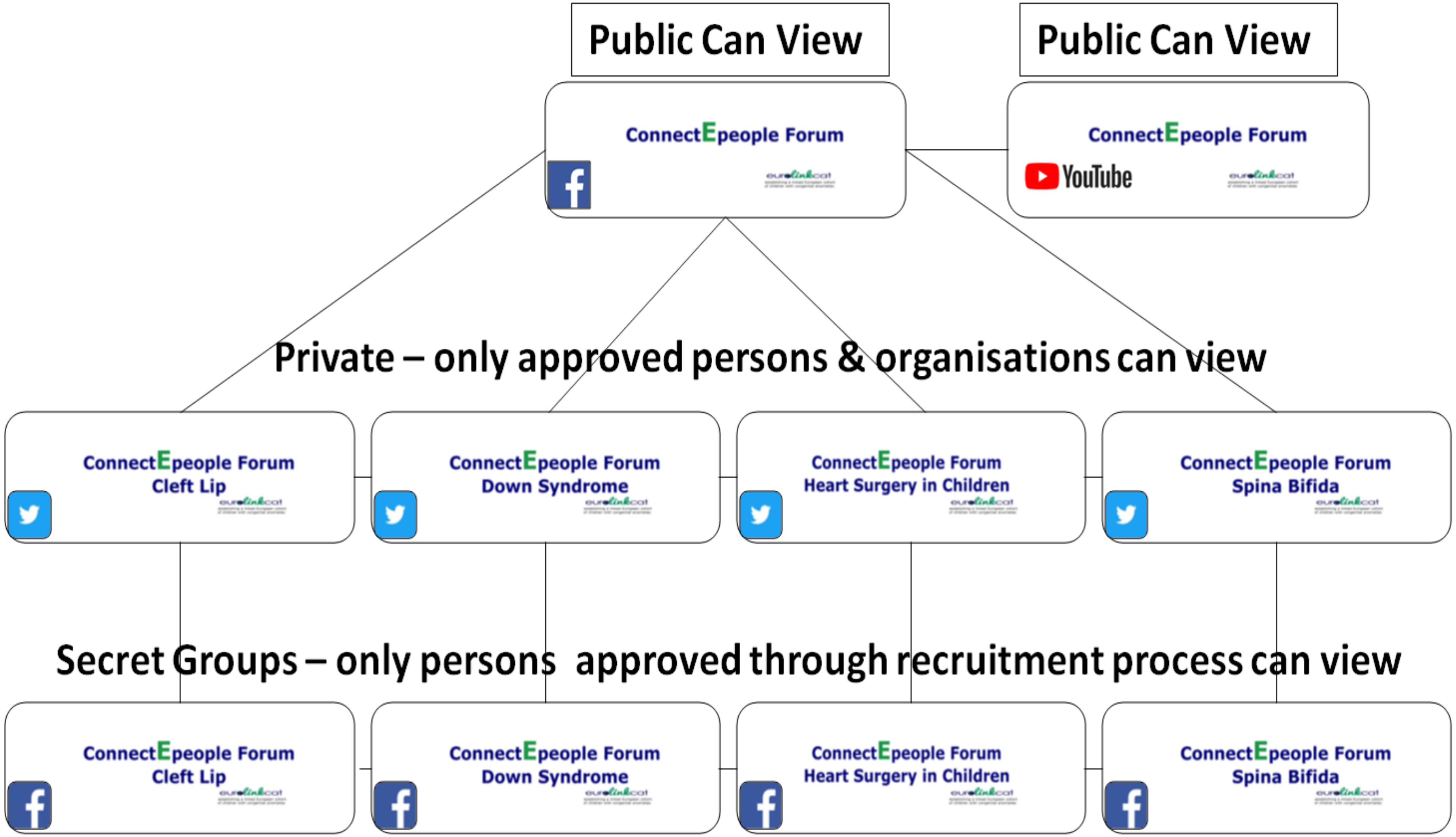
Countries involved in ConnectEpeople



First Step: Design and build an e-forum

The ConnectEpeople e-forum



Public Can View

Public Can View

ConnectEpeople Forum

ConnectEpeople Forum

YouTube

Private – only approved persons & organisations can view

ConnectEpeople Forum
Cleft Lip

ConnectEpeople Forum
Down Syndrome

ConnectEpeople Forum
Heart Surgery in Children

ConnectEpeople Forum
Spina Bifida

Secret Groups – only persons approved through recruitment process can view

ConnectEpeople Forum
Cleft Lip

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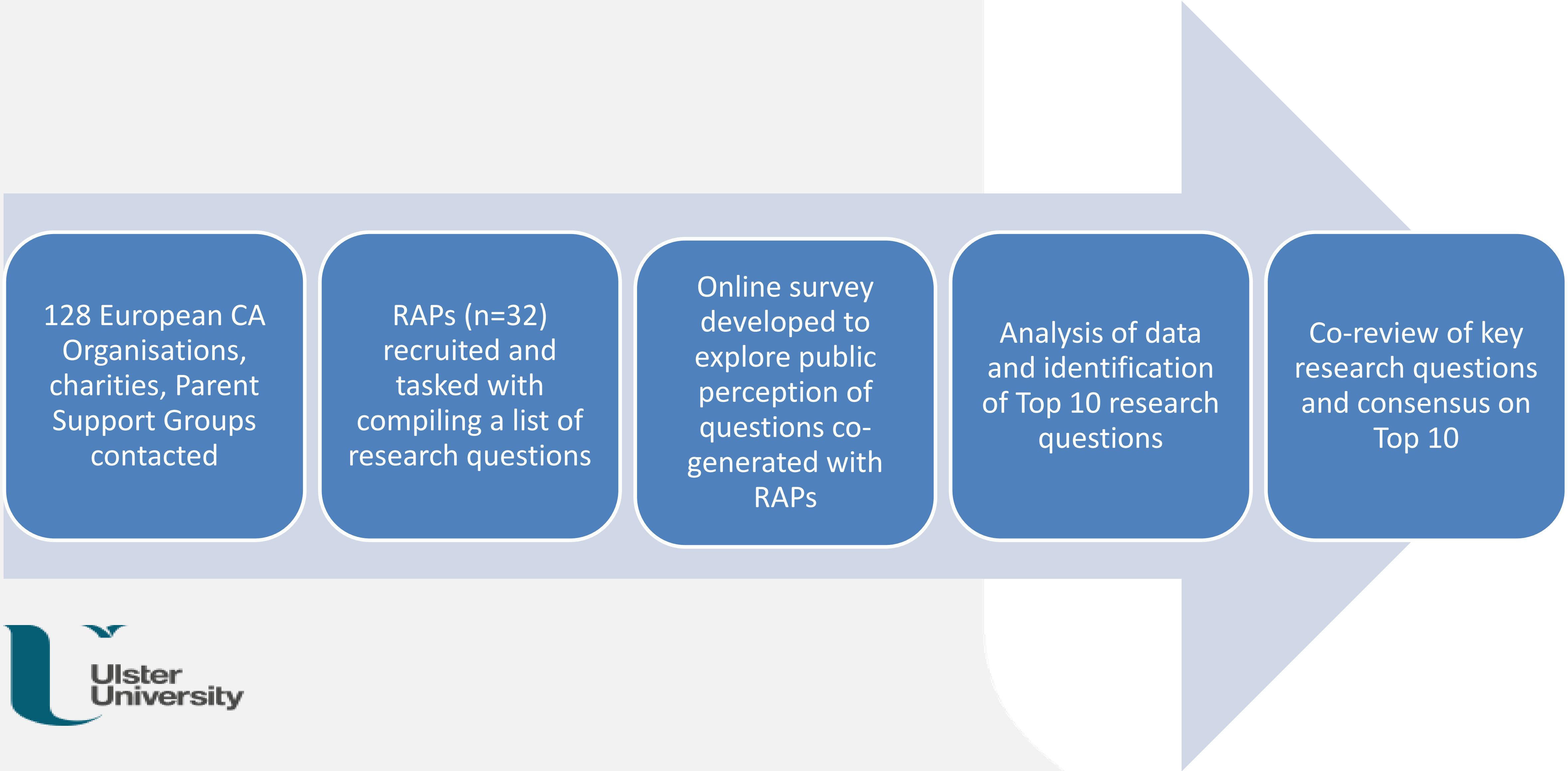
ConnectEpeople Research Engagement Process



- 128 European CA Organisations, charities, Parent Support Groups contacted
- RAPs (n=32) recruited and tasked with compiling a list of research questions
- Online survey developed to explore public perception of questions co-generated with RAPs
- Analysis of data and identification of Top 10 research questions
- Co-review of key research questions and consensus on Top 10

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Online ConnectEpeople Survey Development Process

- 32 RAPs co-produced 98 research questions
- Survey designed using Qualtrics software
- Survey live from 24th May 2018- 8th October 2018
- Languages: English, Polish, Portuguese and Spanish

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Key Findings

- 251 respondents accessed the survey, 248 consented
- 80 completed surveys available for analysis from 17 countries (32% completion rate)
- Descriptive analysis and key research questions identified
- Respondents *rated* the importance of RAPs research questions on Likert scale

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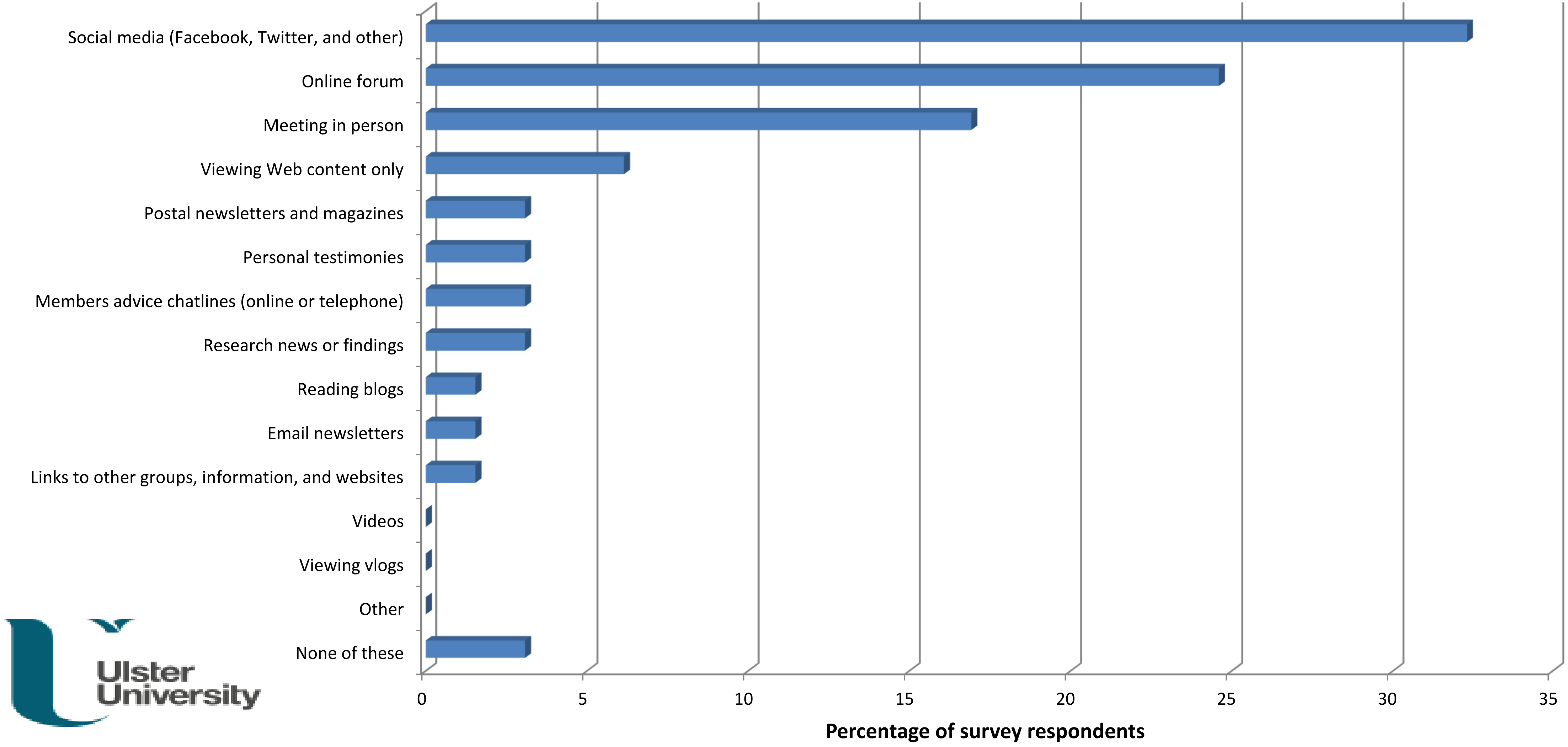
ConnectEpeople survey respondent's communication preferences with support networks (n=65)



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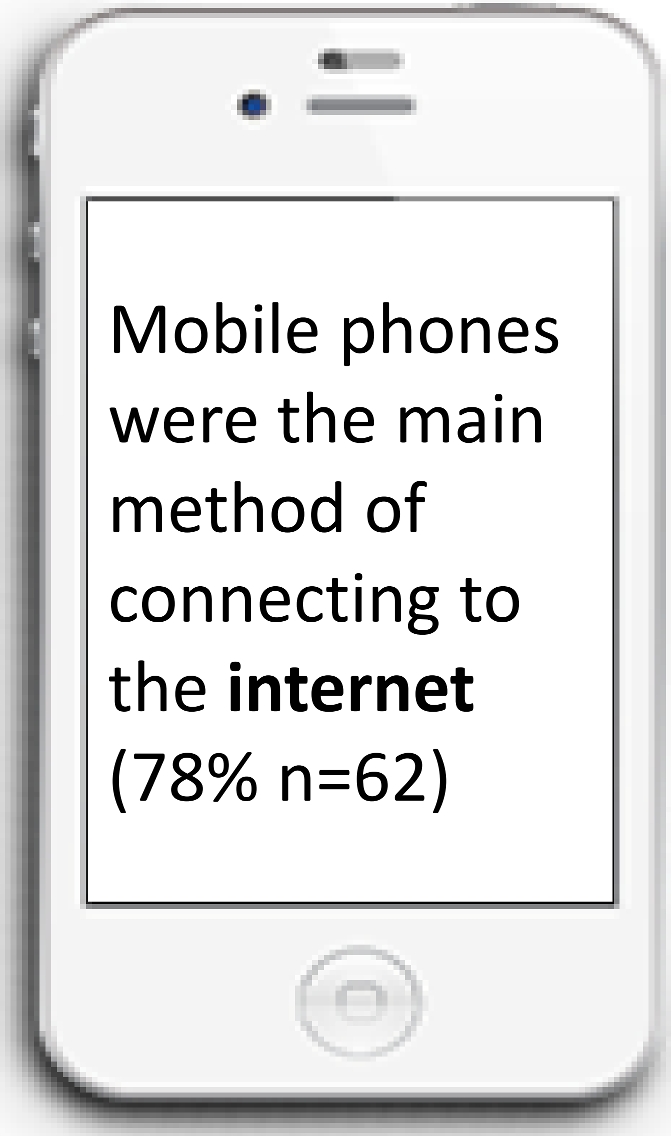
Social media was preferred because of its:

- Accessibility
- speed of contact
- visual choices
- ease of use
- multiple links
- 24-hour availability



Mobile phones were the main method of connecting to the **internet** (78% n=62)

Ranking of the Top 10 research questions using a modified James Lind Alliance approach with RAPs (Morris et al, 2015)

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Shared Research Priorities

Facts: all parents need information about the facts concerning their child’s condition, parents with a child who had CHD considered these questions to be top priority

Health: the majority of parents were concerned about a wide range of health issues, parents of children with DS ranked these the highest

Education: all parents are concerned about the importance of education, parents of children with Spina Bifida ranked these highest

Psychosocial issues: this was ranked to be of equal importance across all groups

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ConnectEpeople Conclusions

- Co-production research facilitated by online channels is preferential in complex family circumstances and where time is limited

- The agreement in research priorities between the survey respondents and the RAPs and the wide geographical engagement suggests a high degree of commonality of the research wants and needs of parents of children with these CA's regardless of location

- In this research we see parents who use 'technology that is manifested in the use of social media' possibly because of its illustrative and graphical potential to optimize visual representation in person first, then in word, text and audio (ocularcentrism) (Sinclair 2011)

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Exploring Research Priorities of Parents Who Have Children With Down Syndrome, Cleft Lip With or Without Cleft Palate, Congenital Heart Defects, or Spina Bifida Using ConnectEpeople: A Social Media Coproduction Research Study

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Thank you

Any questions?

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