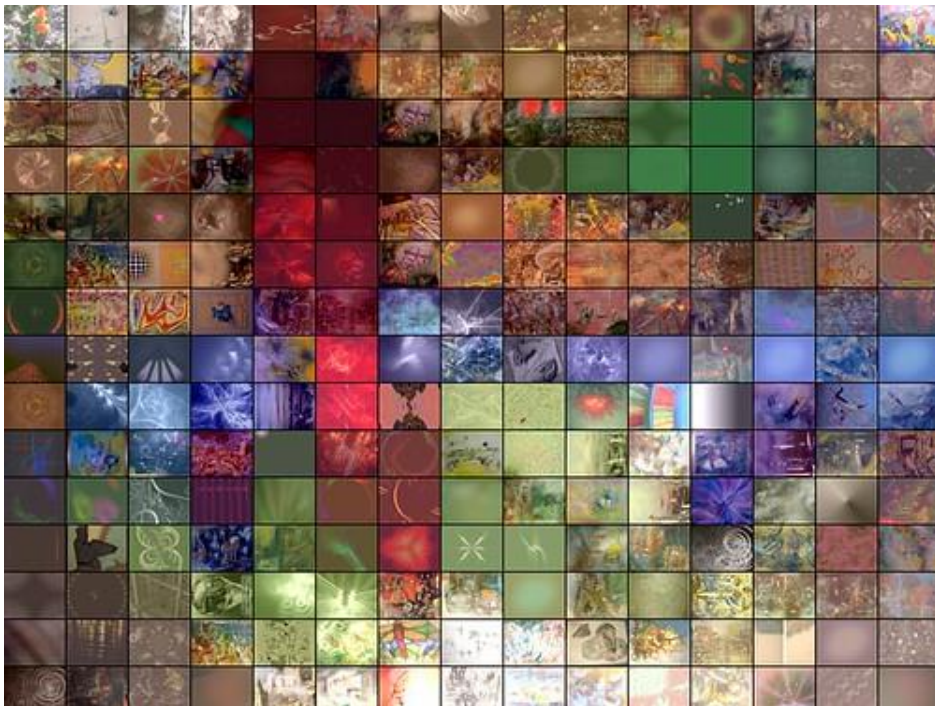


Handling sensitive topics in partnership with young people: Reflections on collaboration within a configurative systematic review



Aim: To explore how and why PPI varies
Question: Who participated, when and how?
Method: 4 purposively selected SRs examined using ACTIVE framework

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Who were public participants in the four reviews?



Diversity in who was involved

Review	Group type	Research experience	Consensus across groups?
MSM	Very well-established	Strong	Yes
Hep C	Well-established	Some	No
Lyme	Well-established	Some	No
ACEs	Not a group	None	N/A

- **Diversity in types of public:** individuals vs groups / established vs less established groups
 - **MSM:** consolidated opinions, confident to engage, consensus of views, able to work together
 - **Hep C / Lyme:** consolidated opinions but no consensus, unable to work together, less experience than MSM
 - **ACEs:** Not an established group, new to being involved in research, and possibly first-time discussing topic
- **Diversity in contribution:** what they bring to the table
 - **Groups:** greater representation of other people's ideas / well-considered positions
 - **Individuals:** more immediate link to current experiences 'coal face' / new and unfiltered ideas
- **Diversity in motivation:** why they get involved
 - **Groups:** representing their 'interests', campaigning
 - **Individuals:** offering knowledge / insight

When and how much were participants involved?

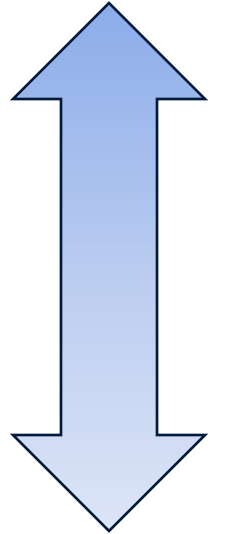
Which stage of the review were participants involved?

- **MSM**: Throughout
- **Hep C**: Question setting (beginning)
- **Lyme**: Interpretation of findings (end)
- **ACEs**: Interpretation of findings (end)



What was the level of involvement?

- **MSM**: Control
- **Hep C**: Control
- **Lyme**: Influence
- **ACEs**: Contribute



Reflections on diversity in level of involvement at different stages:

- Level of involvement can vary at different stages of review – e.g., minor input at question setting, but major input at interpretation stage
- How to define influence? Lyme review provided input via consultations and surveys, suggested language to use and commented on what to include in report i.e., some control but not at question setting stage?
- Involvement in question setting sometimes out of our hands (because policy commissioners set it)

Diversity in stage and level of involvement related to purpose of review and PPI

	Review purpose	PPI purpose
MSM		
Hep C	Instrumental: to inform design of appeals process / compensation	Setting scope: to ensure evidence focused on conditions most important to patients
Lyme	Illumination: Commissioned as part of wide-ranging work map and 4 reviews; NICE concurrently doing effectiveness reviews on diagnosis and management	Interpretation: to ensure relevance of QES findings to UK context
ACEs	Illumination: To understand potential interventions for addressing ACEs, broad area so overview of reviews	Interpretation: to understand relevance and applicability of high-level overview findings

Conclusions