



Background

- Patient and public involvement (PPI) in health research refers to patients and other members of the public with relevant experience contributing to design, implementation, and dissemination of research. PPI entails research being carried out ‘with’ or ‘by’ members of the public, rather than ‘to’, ‘about’ or ‘for’ them.
- Over the past decade, there has been an increased emphasis on the importance of PPI in health and social research as it provides alternative views and insights into the needs of healthcare users to improve the quality and relevance of research.
- PPI enhances the efficiency, design, and quality of healthcare initiatives and facilitates decision-making regarding resource allocations and the usability of services by including information about the capabilities, needs, and priorities of local people.
- The rapid response to the COVID-19 pandemic resulted in PPI being viewed as non-essential, leading to its minimal inclusion in research and, thereby, minimizing the contribution of patients, the public, and, particularly, minority groups in helping find solutions to the pandemic crisis.
- Public health measures (PHM) aim to reduce the transmission, severity of illness, and death and are critical strategies to address pandemic outbreaks, therefore, PPI is crucial in building trust and acceptance in research, greater benefits for the community, new and improved services, valuable changes in practice/partnership leading to positive changes and outcomes.

Research Questions

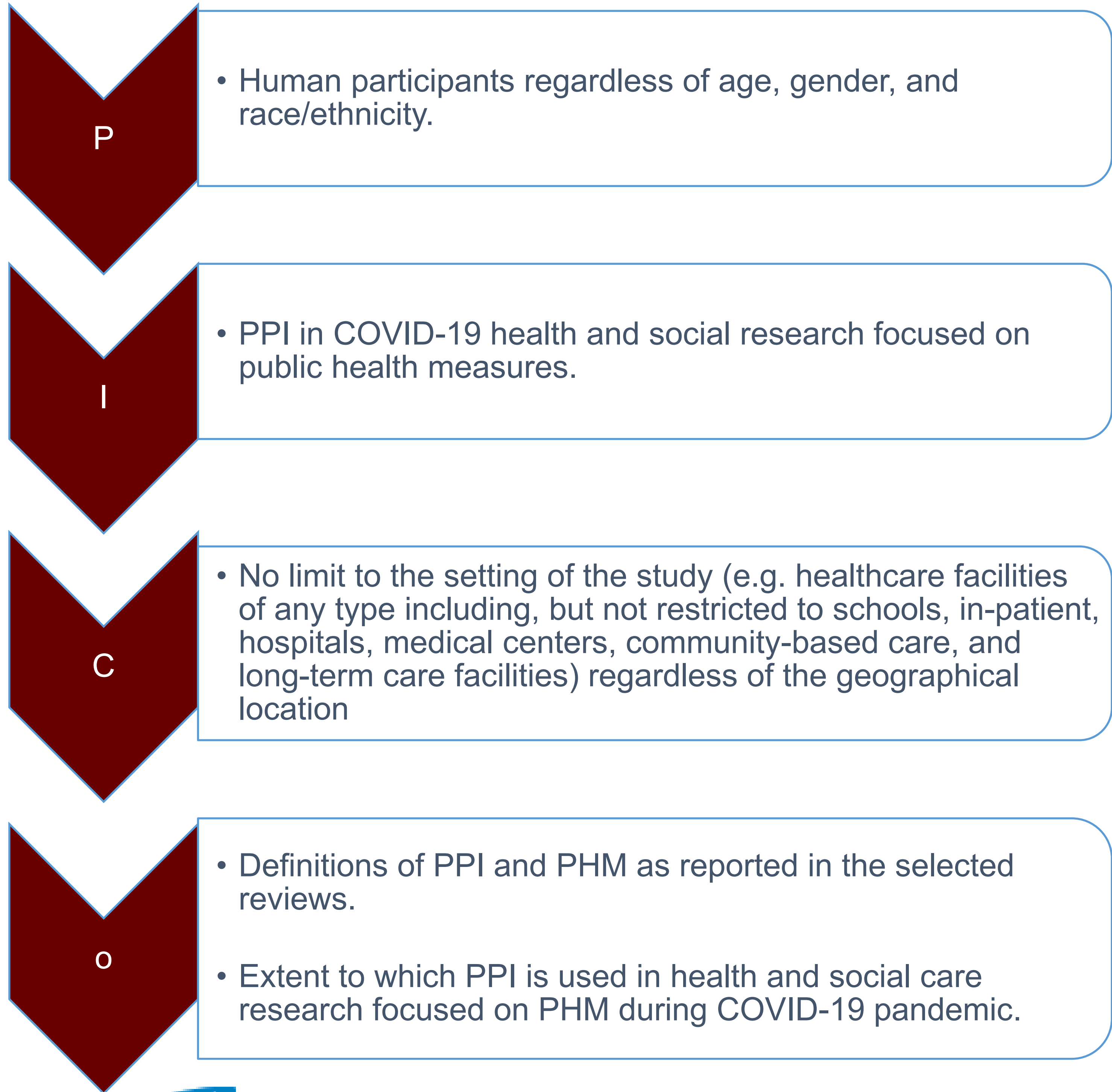
- What were the PPI activities and who/what populations were likely to be left out?
- What are the similarities and differences in the effectiveness of PHM between the systematic review studies?

Aims

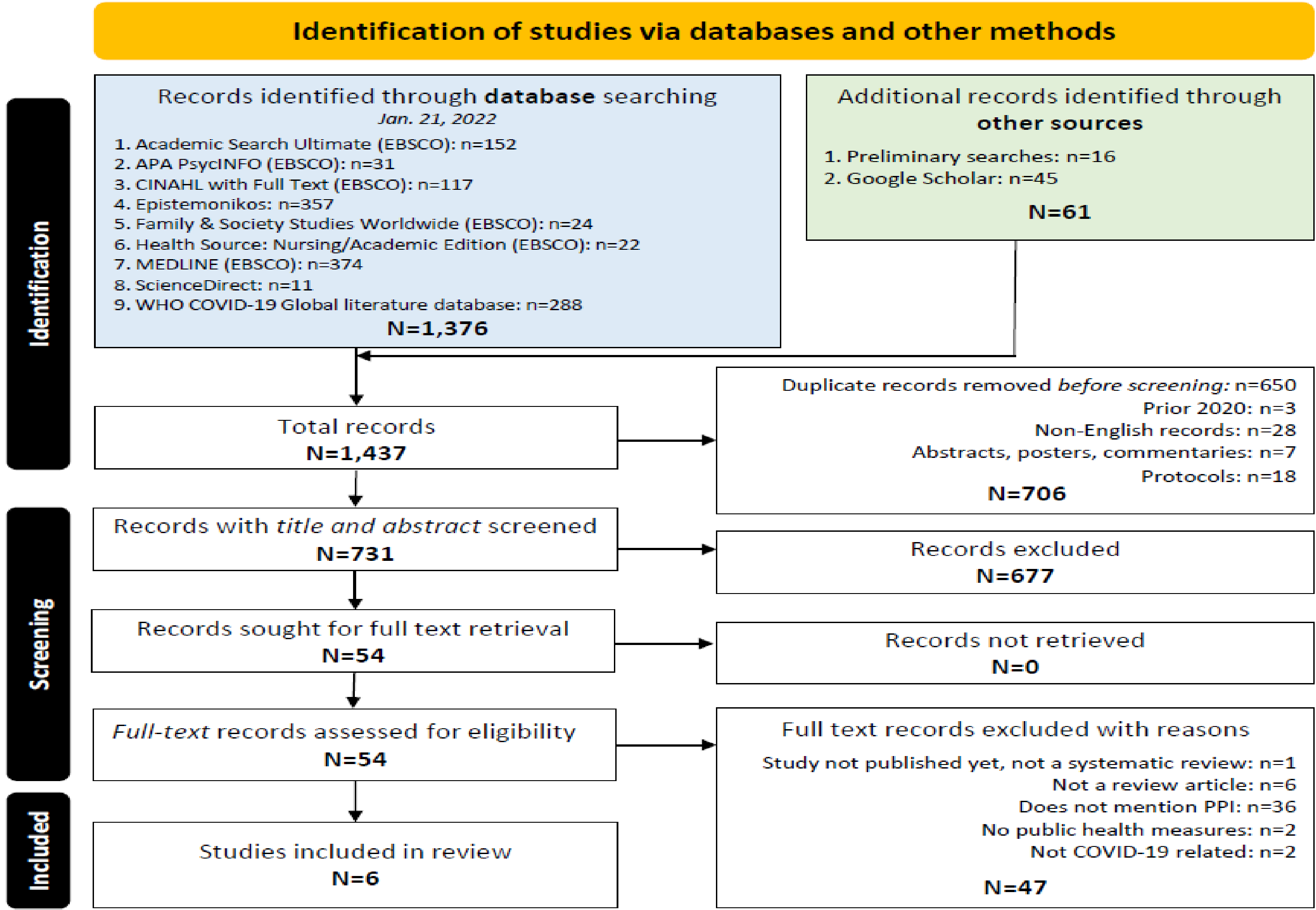
- To determine and describe the nature and extent of the PPI in COVID-19 health and social care research.
- To identify research gaps in PPI to inform future studies and research funding priorities.

Methods

Population, the Phenomena of Interest, and Context (PICo) framework



Results



Summary of Evidence

Author/Year	Synthesized Findings
Adebisi et al., 2021	The majority of African countries have implemented risk communication and community engagement (RCCE) strategies to decrease the prevalence of COVID-19.
Banerjee et al., 2021	Even though the public has shown interest in the development of risk information tools, there has been a lack PPI in the development of risk prediction tools. There is an urgent need to better understand the specific risk information that patients and the public want overall.
Ernawati et al., 2021	Evaluation of society awareness around the knowledge, attitudes, practice (KAP) for the prevention of COVID-19 has been found to be an effective transmission prevention strategy.
Mao et al., 2021	Community engagement and adaptation to change during volunteering efforts were essential in the public’s response to COVID-19 in the UK.
Pegollo et al., 2021	Digital health technologies may bring healthcare services to a large population, which can help individuals feel safe while helping contribute to public health. The acceptance of digital contact tracing (DCT) is mainly centered around knowledge, willingness/adherence, usefulness, accessibility, community empowerment, and the concerns of privacy
Raymond & Ward 2021	Misinformation and fear of being socially chastised resulted in pandemic sanctions, resistance, higher rates of isolation, and increased prevalence rates of the virus. Synthesizing traditional and scientific/medical discourse and practices allowed for innovations and adaptations to communities’ reactions to the pandemic, resulting in community strength and providing methods for successful interactions to improve public health outcomes.

Conclusions

- Volunteerism, community cohesion, and/or the spontaneous development of assistance programs were prevalent in the public response to COVID-19 and should be included when implementing PHM.
- Digital technology should be used by policymakers to include the public in data collection and shared decision making while still respecting privacy concerns of citizens.
- PHM should be tailored to communities and set within a socio-cultural context.
- Successful mitigation efforts should be community specific.
- There was a lack of decision making when patients and the public were involved in PPI
- Further research should be conducted with PPI to determine which PHM could benefit communities and which PHM might cause aversion to adherence.
- PHM that did not have widespread community support or did not consider the socio-cultural context were less likely to be followed.

Limitations

- Conducting an umbrella review on this topic may have been premature due to the limited timeframe available to properly synthesize evidence reviews.
- There was very little review evidence for PPI in the development and implementation of public health measures.

