

# Evaluation of asynchronous online focus groups for use in qualitative studies around patient experience data

Maile Hunter (IQVIA), Matthew Reaney (IQVIA), Stephanie Bean (IQVIA)



## Background

- Both quantitative and qualitative research are useful, either alone or as mixed methods, to understand patient experiences, which both the United States Food and Drug Administration and European Medicine Agency advocate incorporating throughout the medical product life cycle.<sup>1,2</sup>
  - Quantitative patient experience data (PED) is routinely generated through surveys and patient-reported outcome/experience measures (PROMs/PREMs). It can be collected in well-defined and adequately powered samples, although it lacks the depth of insights derived from qualitative research.
  - Qualitative research is typically conducted using in-depth 1:1 interview methods in small samples. However, it can be difficult to conduct qualitative patient experience research in a large sample using traditional methods owing to the significant investment of time and resources required to conduct, analyse, and interpret the data.<sup>3,4</sup>
- Asynchronous online focus groups, otherwise known as online bulletin boards (OBBs), have historically been used to collect data other than patient experience; however, researchers are increasingly using them in innovative fashions to capture PED.
  - OBBs allow researchers to pose several questions to participants over a short period of time via an online platform. Participants engage at their preferred time, location, and pace through “threads” visible to all participants.<sup>5</sup>
  - Participants are expected to respond to the questions posed by the researchers and are encouraged to respond to the comments made by other participants.<sup>6</sup>
- OBBs can be used to generate broad patient insights about disease and treatment; evaluate patients’ priorities, preferences, and needs; provide feedback on PREM/PROM strategies; or investigate acceptability of clinical trial requirements.<sup>7</sup>

## Methods

- A targeted literature review of English language publications from the past five years was conducted in PubMed (June 2021) using the following search terms: “asynchronous online focus group”, “online bulletin board”, “asynchronous online focus groups”, and “online bulletin boards”.
- All abstracts identified in the search (n=47) were critically appraised for relevance and quality. Full-text articles of abstracts provided information about primary PED collection using OBBs (n=13).

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## Results

- Studies collected information from people living with a condition/disease (n=9), caregivers for people living with a condition/disease (n=2), and/or healthcare professionals (n=3).
- The sample size of online focus group studies ranged from 15<sup>8</sup> to 40<sup>6</sup> participants. Two planned studies are proposing larger sample sizes (up to 62<sup>10</sup> and 90<sup>16</sup> participants).
- The reviewed studies had a broad run time, from three days to four weeks. Studies requested varying degrees of participation, from no minimum on how often participants posted<sup>10</sup> to 10 to 30 minutes twice a day<sup>9</sup>, at least once a week. Studies have typically involved 1-2 moderators.

Table 1: Summary of Asynchronous Published Online Focus Group Studies Collecting PED (2016 – Present)

Reference	Population	Objective	# of Participants	Participant Commitment	# of Moderators (Observers)
Arbeit et al. 2016 <sup>9</sup>	Bisexual females	To understand bisexual girls’ perspectives on accessing sexual health information and services	n=40 (total; 4 FG)	3 days	2 (0)
Baron et al. 2018 <sup>8</sup>	Pre-natal persons	To explore the perspectives of prenatal persons, RNs, and other HCPs	n=15 (total; 2 FG)	10 days	2 (0)
Cook 2020 <sup>13</sup>	Persons living with PVNS	To generate insights into the emotional aspects related to living with PVNS	n=11 (total; 1 FG)	4 days	1 (0)
Cook 2019 <sup>12</sup>	Persons living with COPD	To evaluate the effect of cough and mucus on COPD patients	n=20 (total; 2 FG)	2 weeks	1 (0)
Cook 2019 <sup>15</sup>	Persons living with NASH	To understand how patients with NASH perceive their disease, unmet needs, and future treatment	n=16 (total; 1 FG)	4 days	1 (0)
Cook 2019 <sup>17</sup>	Persons living with obesity	To gain insights into the needs, attitudes, perceptions, and preferences of people living with obesity	n=23 (total; 2 FG)	4 days	1 (0)
Fotnot et al. 2020 <sup>5</sup>	Transgender youth	To enhance the understanding of transgender youth HIV risk and experiences with HIV preventive services	n=30 (total; 2 FG)	3 days	1 (3)
Huis in Het Veld et al. 2020 <sup>16</sup>	Caregivers of persons living with dementia	To provide insight into caregiver self-management	n=32 (total; 4 FG)	2 weeks	2 (0)
Patalano et al. 2020 <sup>11</sup>	Persons living with COPD	To gather insights to inform PRO end point selection for persons with COPD	n=20 (total; 1 FG)	2 weeks	Undefined
Ranieri et al. 2019 <sup>16</sup>	Persons living with PSC & caregivers	To explore PSC impacts the psychological well-being of those living with the illness, and those supporting them	n=37-62 (4-10 FG planned)	4 weeks	2 (0)
Ranieri et al. 2021 <sup>10</sup>	HCPs	To describe how COVID-19-related lockdown may impact frontline healthcare workers	n=36-90 (total; 6-9 FG planned)	3 weeks	2 (0)
Rolls et al. 2019 <sup>17</sup>	HCPs	To explore why HCPs belong to an intensive care virtual community	n=23 (total; 3 FG)	3 weeks	1(0)
Whiffin et al. 2020 <sup>* 14</sup>	Neurosurgeons	To understand neurosurgeons’ research experiences in low-income and middle-income countries	n=36 (total; 3 FG planned)	7-10 days	Undefined

\* Publication of study protocol. Outcomes of focus groups not yet published. † Conducted 1:1 interviews upon completion of the FG. COPD: Chronic Obstructive Pulmonary Disease; FG: Focus Group; HCPs: Healthcare Providers; HIV: Human Immunodeficiency Virus; NASH: Non-alcoholic Steatohepatitis; PRO: Patient Reported Outcome; PSC: Primary Sclerosing Cholangitis; PVNS: Pigmented Villonodular Synovitis; RN: Registered Nurse.

## Results (continued)

- Five of the studies conducted follow up phone interviews<sup>6,7,13,14,15</sup> with participants with the goal of discussing any outstanding research topics and obtaining feedback on the online focus groups experience.
- Table 2 shows the advantages and limitations as expressed by participants, coupled with perspectives of the researchers.

Table 2: Advantages and Disadvantages of Asynchronous Online Focus Groups as Expressed by Participants and Researchers

Advantages	Limitations
Ability to convene anonymously and openly with others <sup>7,12</sup>	Internet accessibility and/or knowledge may limit accessibility <sup>12</sup>
Convenience for participants to engage at time and place convenient for them, given other personal and professional commitments <sup>5,6</sup>	Language barriers may exist (moderator and all participants must be able to converse)
Multiple geographies may be included in the sample <sup>14</sup>	Additional interviews needed for those not comfortable using written form of expression <sup>9</sup>
Participants valued the opportunity to share experiences with others similar to themselves <sup>11</sup>	Sample may not be representative of general population <sup>7</sup>

## Discussion

- The OBB format is an efficient method to collect feedback from a sizable sample of respondents (15 or more) in a shorter time and provides flexibility for participants to share experiences, although there are limited examples in the literature to collect PED.
- Given the reliance on an online platform, participation may be limited to those with access to and knowledge of how to use technology.
- This methodology may be particularly appropriate for certain groups, including patients dealing with sensitive health conditions and those with limited schedule flexibility.

## Conclusion

- Asynchronous online focus groups show promise as a methodology to elicit PED; however, further studies are needed to build the body of evidence supporting this research technique.
- Researchers who leverage this technology should share tips and tricks to enable others to incorporate this methodology in a manner that avoids common stumbling blocks.
- Future engagement with regulators is needed to understand the acceptability of this research methodology in that context, as well as by other stakeholders.