

Original Article

Medical Summary Template for the Transfer of Patients with Inflammatory Bowel Disease from Pediatric to Adult Care

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Abstract

Background: The transfer of information is a key aspect of the transition of adolescent patients with inflammatory bowel disease (IBD) from pediatric to adult care. This is typically accomplished through the use of a consultation letter with a medical summary of the patient being transferred. To improve the quality and completeness of information included in a transfer letter, we developed a standardized medical summary template by integrating the feedback of adult and pediatric health care providers.

Methods: To develop the letter template, we purposively sampled gastroenterologists or nurse practitioners caring for patients with IBD in four Canadian cities and invited them to take part in focus group discussions. Using a semi-structured approach, we explored the items deemed essential for inclusion in a transfer summary. Using the conventional content analysis framework, the focus group discussions were inductively coded to identify areas of priority for inclusion in the template.

Results: Four focus groups were conducted, comprising 17 health care providers of 30 invited (56.7% participation). The resulting medical summary template included the following major headings: patient/disease characteristics, therapeutics history (including medications and surgeries), clinical history and current status, noteworthy investigations, history of complications (including hospitalizations), family history, immunization history and psychosocial history. The template also addressed health system process factors (i.e., urgency of transfer, mode of delivery and confidentiality) to ensure a seamless transfer to adult care.

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Conclusions: The standardized medical summary template should be used by pediatric providers to ensure that essential patient information and disease characteristics are sent to an adult provider.

Keywords: *Crohn's disease; Health services research; Inflammatory bowel disease; Pediatrics; Qualitative research; Transition from pediatric to adult care; Ulcerative colitis*

Introduction

Inflammatory bowel disease (IBD), and its two main subtypes Crohn's disease (CD) and ulcerative colitis (UC), are chronic, immune-mediated inflammatory diseases affecting the gastrointestinal tract. They are lifelong conditions requiring ongoing medical therapy to decrease the inflammatory burden on the gastrointestinal tract and other body systems, thereby reducing the risk of complications. While the incidence of IBD has plateaued in adults living in the Western world (1), the incidence is still rising in pediatrics (2), particularly among children under 10 years old (3). In Canada, the prevalence of IBD in children <18 years old is expected to triple by 2030 (4). Therefore, more adolescents will transition from pediatric to adult care for their IBD.

Transition is defined as the process of changing from a pediatric to adult health care model, including medical, psychosocial, and educational preparation and physical transition (5). It is a multi-faceted active approach to address the needs of adolescents as they move from child-oriented to adult-oriented care. The transition process ultimately culminates in the transfer from a pediatric to an adult care provider, although patient adjustment to adult care continues after transfer. In the case of patients with IBD, the transfer typically requires a request for consultation from the pediatric gastroenterologist to the adult provider, accompanied by a summary letter describing the details of the patient's disease, treatments, complications and psychosocial history (6,7). In a survey of adult gastroenterologists, the sub-optimal quality of the documentation sent by pediatricians was identified as one of the barriers to a successful transfer to adult care (8,9). A template for a transfer letter was included in the transition guidelines produced by The North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) (10). However, this document is nearly 20 years old, and there have been many intervening changes to the care of children with IBD, including the rise of biologic therapy.

The aim of this study was to create a standardized medical summary template which would guide pediatric gastroenterologists in providing adult gastroenterologists with the information required to facilitate the transfer of patient care. We used the information from focus groups of providers to create a transfer letter template that could feasibly be incorporated into practice.

METHODS

This project was approved by the Research Ethics Boards of the Children's Hospital of Eastern Ontario and McGill University Health Centre. This manuscript was written in compliance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) reporting guidelines (11).

Study Design

We convened four focus groups and used a semi-structured approach to explore the topic that should be included in a medical summary letter. The focus groups consisted of the following participants: (1) adult gastroenterologists in Ottawa, Canada (moderators: E.I.B., D.L.); (2) adult gastroenterologists in Montreal and Sherbrooke, Canada (moderators: W.A., D.L.); (3) pediatric gastroenterologists and nurse practitioners in Ottawa, Montreal, Toronto or Vancouver, Canada (moderator: E.I.B.); (4) a mixed group consisting of most participants from the preceding three focus groups (moderator: E.I.B.). All focus groups were recorded with participant consent and later transcribed verbatim. The first two focus groups of adult providers were conducted independently (information from each group was not shared with the other) and the transcripts/recordings were analyzed separately, however the resulting qualitative data were presented as a single combined evaluation. The third focus group of pediatric providers was exposed to the preliminary results of the first two focus groups since it was expected to elicit feedback on the acceptability of the adult providers' preferences. The final focus group, consisting of both pediatric and adult providers, was provided the results of the qualitative analysis and prioritization of the first three groups, as well as a draft letter template for review. This final group evaluated the template for completeness and useability and clarified any outstanding matters from the discussions at previous meetings. The proposed template was reviewed for the preferred content areas of the medical summary template, with revisions incorporated in real time until the final version was achieved. Participants could incorporate parts of the NASPGHAN template into their suggestions for a new template, but it was not intended to be the basis for the new template.

Discussions were held in English, except for the second group (adult gastroenterologists in Montreal) which was held in French, and the transcription was translated to English for analysis. The moderators of the first two focus groups guided each group discussion using a focus group guide developed a

priori ([Supplementary Digital Content 1](#)) and provided spontaneous questions and prompts to clarify points and follow emerging topics of interest raised by the participants. D.L. acted as a participant (not moderator) of the third pediatric focus group. D.L. and W.A. acted as participants in the fourth overall focus group. The participants were familiar with the moderators from previous professional interactions. There were no nonparticipants present.

Participants

Purposive sampling was used to identify participants for the focus groups. Participants were eligible for inclusion if they were gastroenterologists or physicians caring for patients with IBD, resided in Ottawa, Montreal or Vancouver, and could communicate fluently in English or French. Gastroenterologists caring for <50 IBD patients in the past two years were excluded. Invitation emails were sent by the investigators to 30 local academic or community-based physicians, of whom 17 (56.7%) agreed to participate.

Data Collection Setting

The first three focus groups took place at dinner meetings in Ottawa (July 9, 2018), Montreal (February 13, 2019) and Toronto (January 11, 2020). The final focus group took place virtually (June 8, 2020) using GoToMeeting software (LogMeIn Inc., Boston, MA). Each focus group lasted between 60 and 90 minutes and was audio- and video-recorded for subsequent transcription by a professional transcription company (Brisson Traduction, Montreal, Canada).

Data Analysis

Informed by conventional content analysis (12), we inductively coded the transcripts to identify all areas of discussion within the dataset relevant to the underlying question. Analysis was led by one member of the study team (D.N.) with regular input from the larger team via team debriefing meetings. Nvivo 12 (QSR International, Burlington, MA), a qualitative data analysis software package, was used to facilitate the coding process. Codes were organized into broader categories related to the possible content areas of the medical summary template, as well as categories related to the letter's general organization, attachments, recipients and modes of delivery and other concerns (e.g., implications of regional differences in practice, electronic medical records and the inclusion of sensitive information). While no formal voting was undertaken, for coding purposes, potential items were also organized into one of three domains when the data permitted: these included items deemed very important by participants (i.e., must be included in the transfer letter), items deemed somewhat important (i.e., could be included the transfer letter), and items deemed not important (i.e., could be excluded from the transfer letter).

This organization was subjective based on inferences from participants' language. Analysis occurred between each round of focus groups so that preliminary findings could inform the creation of the evolving template letter and guide further data collection.

RESULTS

Participant Demographics

Demographic characteristics of the focus group participants are summarized in [Table 1](#). Twelve adult gastroenterologists participated in the first two focus groups. Six pediatric providers (five pediatric gastroenterologists and one nurse practitioner) participated in the third focus group. Fifteen participants (of the 18 eligible providers) attended the final focus group. The three providers unable to participate in the final focus group (due to scheduling conflicts) reviewed the summary data derived from the first three focus groups and final template.

Medical Summary Template

The medical summary letter template is provided in [Table 2](#), which was developed based on the qualitative findings from

Table 1. Demographic characteristics of focus group participants

	Providers (n = 18)
Gender, Female (%)	10 (55.6%)
Age, median (IQR)	45.5 (42, 50)
Province of practice	
Ontario	9 (50.0%)
Québec	8 (44.4%)
British Columbia	1 (5.6%)
Practice type	
Academic	15 (83.3%)
Community-based	3 (16.7%)
Specialty	
Adult	12 (66.7%)
Pediatric	6 (33.3%)
Years in practice, median (IQR)	15.0 (10.0, 20.7)
IBD patients treated per month, median (IQR)	75 (40.0, 100.0)
Proportion of practice consisting of IBD patients, median (IQR)	0.725 (0.525, 0.875)
Number of transitioning adolescents IBD patients per month	
Pediatric GI (patients transferred), median (IQR)	3.75 (1.75, 5.0)
Adult GI (patients received), median (IQR)	1.75 (1.375, 3.125)

GI, Gastroenterologist; IBD, Inflammatory bowel disease; IQR, Interquartile range.

Table 2. Template for the medical summary transfer letter

	Requests
From adult gastroenterologists	<ul style="list-style-type: none"> • Priority of transfer: <ul style="list-style-type: none"> • Urgent (within 3 months) • Semi-urgent (within 6 months) • Non-urgent (within 12 months, or within 6–12 months of 18th birthday) • Two methods of delivery to ensure receipt (e.g., fax, email, mail) • Provide information in point-form or table format, chronologic order
From pediatric gastroenterologists	<ul style="list-style-type: none"> • Notification that patient has been accepted for transfer and target date for appointment • Notification that patient has been seen by adult gastroenterologist • Consultation letter from adult gastroenterologist once patient has been seen (within a reasonable period of time)
Copies of letter to be sent to:	<ul style="list-style-type: none"> • Adult gastroenterologist • Family physician • Other specialists involved in care • Patient
Patient/disease characteristics	
Demographics	<ul style="list-style-type: none"> • Date of birth (Age) • Biologic sex and gender identity (if different from sex) • Patient's contact information (verified by pediatric team)
Diagnosis and phenotype	<ul style="list-style-type: none"> • Date of diagnosis (at minimum, year of diagnosis) • Disease type (CD, UC or IBD-U) • Disease location • Phenotype (Paris or Montreal classification)
Comorbidities/other chronic diagnoses	<ul style="list-style-type: none"> • Related to IBD • Unrelated to IBD
Allergies	<ul style="list-style-type: none"> • Medications • Other
Therapeutics	
Medications	
Current and Historic	<ul style="list-style-type: none"> • Name and dose • Dates (starting and discontinuation) • History of nonadherence (brief) • Reasons for stopping if applicable (e.g., side effects, complications, compliance)
Biologics	<ul style="list-style-type: none"> • Dose and interval (at initial induction) • Dose and interval (currently) • Reasons for escalation/de-escalation • Recent serum titers (Alternative: report in Labs section below)
Corticosteroid history	<ul style="list-style-type: none"> • Number of courses • Last course (dates) • Responsiveness
Surgeries	
Historic	<ul style="list-style-type: none"> • Date • Surgery description (including length of bowel resected if available) • Pathology results • Reason for surgery • Complications (if applicable) (Alternative: report in Complications section below)

Table 2. Continued

	Requests
Clinical history and current status	
History of presenting illness	<ul style="list-style-type: none"> • Initial presentation at diagnosis (brief description of initial presentation and clinical course)
Current status	<ul style="list-style-type: none"> • Status: Stable/controlled or unstable/uncontrolled (provide disease activity index if possible) • Most recent weight and height (include history of growth failure, if applicable) • Significant physical findings, if applicable
Investigations	
Imaging: endoscopies	<ul style="list-style-type: none"> • Description of endoscopy at diagnosis (including date, disease location, severity, pathology results) • Description of last endoscopy (including date, disease location, severity, pathology results) • Description of video capsule endoscopy (including date, disease location, severity) • Brief listing of other endoscopies (date, results), or attach endoscopy and pathology reports as addendum • If applicable, was cancer surveillance colonoscopy conducted or discussed with the family?
Imaging: radiology	<ul style="list-style-type: none"> • Initial radiology results (especially small bowel imaging) • Most recent small bowel imaging • If applicable, bone density and CT scans or attach all radiology reports as addendum
Labs: previous noteworthy investigations	<ul style="list-style-type: none"> • TPMT status • Viral serologies (Hepatitis A, Hepatitis B, Hepatitis C, CMV, EBV, Varicella) • Tuberculosis testing results • IBD-related antibody serology results
Labs: recent investigation	<ul style="list-style-type: none"> • Most recent laboratory investigations • Most recent serum drug titers (with dose/interval of medication administration) • Fecal calprotectin
History of complications	
Hospitalizations	<ul style="list-style-type: none"> • List all hospitalizations with dates, reason for hospitalization, and brief description of clinical course
Other complications	<ul style="list-style-type: none"> • If not listed under comorbidities above, highlight complications due to IBD or medications (especially hematologic, rheumatologic, dermatologic, ophthalmologic, bone health)
Other:	
Family history	<ul style="list-style-type: none"> • Where applicable, relevant family history (IBD, cancer)
Immunization history	<ul style="list-style-type: none"> • If available • If not available, should report this. • List of immunizations that are missing or due to be given
Psychosocial	<ul style="list-style-type: none"> • If applicable, history of mental illness, substance abuse, psychosocial risk factors • Current and historic smoking status (including vaping) • Current and historic cannabis use • Current and historic alcohol use • Living situation, family conflict
	<i>Note: Sensitive information may be sent separately or as an attachment if patient confidentiality may be compromised</i>

Table 2. Continued

	Requests
Attachments	
Suggested attachments	<ul style="list-style-type: none"> • Endoscopies reports and pathology results • Video capsule endoscopy reports • Surgical and related pathology reports • Relevant radiology reports (small bowel imaging, bone density) • Hospital discharge summaries for noteworthy hospitalizations • Consultation reports and most recent clinical report from other specialist physicians involved with patient care (rheumatology, dermatology, hematology, ophthalmology)

CD, Crohn's disease; CMV, Cytomegalovirus; EBV, Epstein Barr virus; IBD, Inflammatory bowel disease; IBD-U, IBD type unclassified; TPMT, Thiopurine methyltransferase; UC, Ulcerative colitis.

the four focus groups ([Supplementary Digital Content 2](#)). Focus group participants suggested the following headings for the medical summary letter: patient/disease characteristics, therapeutics history (including medications and surgeries), clinical history and current status, noteworthy investigations, history of complications (including hospitalizations), family history, immunization history and psychosocial history. In addition, a number of suggested attachments should be provided with the medical summary, including endoscopy and surgery reports with corresponding pathology reports, relevant radiology reports (focused on small bowel imaging and bone density testing), hospital discharge summaries for noteworthy hospitalizations and consultation reports from other involved specialist physicians.

For the most part, participants shared similar experiences, and agreed on suggestions for items to be included in the medical summary template. In the adult provider groups, there were minor disagreements with respect to the location of communication of treatment adherence history ([Supplementary Digital Content 2](#), quotations (Q) 1.4–1.8) and sensitive information, including psychosocial history (Q1.24–1.25). There were varying opinions on whether laboratory investigations should be included (Q1.31–1.34), and whether some or all serum biologic titers should be provided (Q1.35–1.38). In the pediatric providers group, there was debate as to the volume of medication history that should be provided (Q2.2–2.4), whether tuberculosis skin test results should be transmitted (Q2.5), and the transmission of sensitive psychosocial information (Q2.9–2.14).

Specific Health Care Provider Requests

Adult gastroenterologists requested that the letter be preceded by a transfer priority provided by the pediatric gastroenterologist to aid in the triaging process (urgent, semi-urgent, or non-urgent), with suggested wait times provided by participants

([Table 2](#)). In addition, the summary letter and transfer package should be sent using two methods of delivery (e.g., electronic, mail and/or fax) to ensure receipt, although electronic delivery may be the sole method if immediate electronic confirmation receipt is available (Q1.50–1.51, Q2.29–2.33). While the adult gastroenterologists appreciated completeness of the medical summary letter, they also felt that overly lengthy letters could result in missed information (Q1.45–1.48). They felt that summaries written in point-form could help alleviate this concern (Q1.42). The pediatric providers requested notification that the transfer had been accepted by the adult providers, and a target date for the first consultation appointment. They also requested that once the patient was seen, a consultation letter be sent to the referring provider within a reasonable period of time in order to confirm the completion of the transfer process. Finally, the adult and pediatric providers agreed that copies of the summary letter be sent to the consulting adult gastroenterologist, the primary care provider, other specialists involved in the patient's care, and the patient (not the parents) (Q2.22–2.28). The patient should receive a copy of the medical summary letter for their own information and education, in case of the need for emergency health care prior to transfer to adult care. Participants acknowledged that this could present difficulties with the relaying of sensitive psychosocial information to the adult provider. The patient may not want this information transmitted to the adult provider (despite its importance for the provision of adequate health care), or the summary could be intercepted by a party without permission to view this information (such as parents) (Q1.22–1.23, Q2.10–2.11). Therefore, sensitive information should not be transmitted in the medical summary letter, and instead should be relayed to the adult provider by other means (e.g., telephone or secure electronic messaging) (Q2.22–2.25). The plan for transmission of sensitive information should also be reviewed with the patient to ensure consent (Q2.11).

Discussion

The transition from pediatric to adult care for adolescents with chronic diseases is multi-faceted, but ultimately culminates in the transfer of the patient from the pediatric to adult health provider. This transfer period has been identified as a time of vulnerability for the adolescent, and incomplete information sent by the pediatric providers to adult consultants may result in medical error, wasted health care resources, and distrust of the health system by the patient and family. A medical summary sent from the pediatric to adult gastroenterologist has been identified as a key part of the transfer process (6,7). To ensure a comprehensive template for the medical summary transfer letter, we used focus groups to explore the interests and needs of both pediatric and adult providers. This template will allow for comprehensive communication of information at the time of the transfer to adult care.

Transition for young adults with special health care needs has been identified as a health services priority area (13). Studies have reported a higher economic burden among young adults with pediatric-onset IBD (14,15). IBD patients were more likely to visit the emergency department in the years following transfer to adult care, but hospitalization rates were not increased indicating that the emergency department visits could have been avoided with adequate outpatient support (16,17). Part of adequate care provision is the effective communication of medical information between health care providers at the time of transfer (18). Adult gastroenterologists reported that provision of the medical summary by the pediatric gastroenterologist before the first visit with an adult provider was of utmost importance, yet 51% reported that this was often a problem (8). A Delphi study of 37 international experts in adolescent health reported that assuring good coordination between pediatric and adult professionals (including communication) was the most important indicator of a successful transition (19). The provision of a written health summary and bio-psychosocial profile to the patient and adult care provider before transfer was considered essential or very important by 89% of experts (19). In a recent needs assessment of Canadian health care providers, 84.7% of adult gastroenterologists and allied health providers said medical summaries were important tools, compared with 62.5% of pediatric gastroenterologists ($P = 0.06$) (20). Of adult providers, 82.6% preferred to obtain a medical summary prior to the first transfer visit (20). Medical experts interviewed as part of this study provided both suggestions of what should be included in the medical transfer summary, but also modes of delivery (to ensure redundancy) and a prioritization strategy to help with triaging of cases. These strategies could help to address the gap identified in earlier studies (8).

In 2002, NASPGHAN produced a medical position statement for adolescents and young adults with IBD transitioning from pediatric to adult care (10). As part of this statement, a

medical summary template was provided, developed based on expert opinion. However, this template was created before widespread use of biologics in children with IBD, and did not include important aspects of modern care such as standardized phenotyping (21), therapeutic drug monitoring, anticipatory guidance or vaccination history. In our study, the adult and pediatric focus group participants reviewed the NASPGHAN template and found it lacking information deemed important to the modern care of patients with IBD. They built upon this template to create a new and more expansive summary template which could facilitate the transfer to adult IBD care. This included the patient's medical history, their current therapies and clinical status, their psychosocial risk profile, and the anticipatory guidance and preventive medicine provided by the pediatric team. In addition, our template includes important recommendations on triaging of patients, suggestions for transmission methods and the importance of receipt confirmation and an acknowledgement of the important role of psychosocial health in the transitioning adolescent.

Participants in our focus groups emphasized the importance of the patient receiving a copy of their medical summary, but acknowledged that sensitive information should be left out of this summary in case it is intercepted by someone other than the patient (e.g., a parent opening the patient's mail). However, the importance of the patient bringing their summary to their first adult gastroenterologist appointment was acknowledged by IBD care providers in our groups and others (22). This again ensures redundancy in the system to relay information from the pediatric to adult health care provider.

The strengths of our study are its direct application to clinical care, providing a template that can be easily be applied to clinical practice. In addition, our rigorous qualitative research methodology and iterative focus groups are unique. The information from adult gastroenterologists were provided to pediatric gastroenterologists for review and comment, and then all comments were systematically provided to all participants for their final comments and approval. Each stage of the process was analyzed using the same methodology by a qualitative research analyst who was not present and did not participate in the focus groups, reducing the risk of bias. To our knowledge, this is the first time adult and pediatric provider suggestions have been integrated to create a transition tool, therefore this tool should be acceptable to both types of care providers.

Our study has some limitations. Since the analyst was not present during the focus group discussion, he relied on transcripts of the discussions to conduct the analysis, which may have introduced bias. However, the audio and video recordings were available to him in case of uncertainty. Some of the investigators participated in the third and fourth focus groups, which may have introduced bias. However, these groups were not 'blinded' to the results of the first two focus groups (which

were conducted independently), and therefore the investigators were not privy to any results that were not made available to the other participants of the third and fourth focus groups. In addition, the investigators who participated were clinicians with an active role in caring for transitioning IBD patients, and therefore we felt that their viewpoints were important to reflect in the final template. While a strength of this study is its multi-site nature involving both adult and pediatric providers, including academic and community practitioners, with representation from IBD nurse practitioners, all providers were from four Canadian cities. Therefore, the interests of rural providers may not be represented, and the resulting summary template may be biased toward the Canadian health care setting. However, treatment of IBD patients in Canada universal health care system is similar to Europe, including the age at which the transfer occurs (16–18 years old). While other health systems may function differently, most of the issues and concerns raised by the focus groups are universal and should apply to the international audience. Finally, the summary template requires more detailed information than the NASPGHAN document, and therefore transfer letters may take longer to create. However, with the availability of electronic health records, the data required by our summary template are readily available, and modern systems can fill much of the template using macros to auto-populate the information.

In summary, we have produced a medical summary template for use by pediatric IBD care providers in creating transfer-of-care letters to adult gastroenterologists. The transition from pediatric to adult care is a gradual, multi-faceted process involving the patient, family, and pediatric and adult health care providers. It culminates in the transfer of care to an adult practitioner, which requires a complete transfer of information between health care teams and appropriate triaging of urgent cases. This medical summary template ensures that all important aspects of IBD care are communicated to the receiving providers, including the patient's history, clinical status and psychosocial health. This will help the adult gastroenterologists appropriately triage the patient, understand their medical history and provide high-quality health care.

SUPPLEMENTARY DATA

Supplementary data are available at *Journal of the Canadian Association of Gastroenterology* online.

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CONFLICT OF INTEREST

E.I.B.: Legal consulting for Hoffman La-Roche Limited and Peabody & Arnold LLP for matters unrelated to a medication used to treat inflammatory bowel disease. W.A.: Speaker, advisory board member, and/or clinical investigator for Abbvie, Amgen, Arena Pharmaceuticals, Dynacare, Eli-Lilly, Janssen, Merck, Novartis, Pfizer, Prometheus, Sandoz, Takeda, Theradiag. S.P.: Speaker for Abbvie, Janssen, Takeda. D.L.: Speaker for Janssen. TRACC received unrestricted educational funding from Abbvie and Janssen Canada. These companies were not involved in the design, conduct, analysis or interpretation of this study.

AUTHOR CONTRIBUTIONS

E.I.B.: Study conception and design, data acquisition, interpretation of the data, drafting the manuscript and final approval of the manuscript. W.A.: Study conception and design, data acquisition, interpretation of the data, editing and final approval of the manuscript. S.P.: Study conception and design, data acquisition, interpretation of the data, editing and final approval of the manuscript. D.N.: Qualitative data analysis, interpretation of the data, editing and final approval of the manuscript. S.G.N.: Study conception and design, interpretation of the data, editing and final approval of the manuscript. D.L.: Study conception and design, data acquisition, interpretation of the data, editing and final approval of the manuscript.

DATA AVAILABILITY

The raw qualitative analysis data for this study were provided in [Supplementary Digital Content 2](#). The focus group audio/video recordings and transcripts have not been shared to protect the privacy of participants, but are available upon request.

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