Supplementary Online Content

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eAppendix. EQUALITY Stakeholder Advisory Board: Selected Feedback

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This supplementary material has been provided by the authors to give readers additional information about their work.

eAppendix. EQUALITY Stakeholder Advisory Board: Selected Feedback

In-depth Interviews

- Race and Ethnicity
 - African American participants: Data represents a wide range of participants, including black gay males, bisexual males, and transgender women.
 - Response of black trans patients: We've heard various experiences within the trans community in interviews so far. We're looking to interview more trans participants due to this variation within the transgender population
 - Differences across racial and ethnic groups: It's early to conclude differences, however so far in interviews the idea of intersexuality has come up.

o Age of Patient Participants

- Older and younger participants have different perspectives and experiences. Older participants have provided stories from 1960s-80s and have been able to compare to present-day
- We are keeping in mind these generational gaps as we analyze the data, along with educational level and how that impact patient experience

o Importance of Asking Patients

- Provider quotes reflect fundamental biases and lack of knowledge
- Awareness of not only would be beneficial to patients themselves, but at the broader policy and systems level as well
- Importance of the Patient Voice: Talking to providers we would not have the rich insight that we do

o Cultural Sensitivity of Providers & Barriers in Implementing Training

- Lack of Education: One of the biggest barriers is that we don't teach health care students before
 they begin in the field practicing and develop habits. Need the integration of training about LGBT
 cultural and clinical competency into primary education
- It's about culture change and doing it over time

Medical Irrelevance

- Normalization of process of collecting SO/GI information will help decrease the barrier. If providers are used to asking this information, it will help decrease discomfort among providers. For example, asking about race/religion.
- Including the question as a check box in demographic information might help normalize the process.
- If the provider is aware of the impact of not asking these questions, they might be more likely to ask it. This might help normalize the process as well.
- Data regarding patient satisfaction are available. We can look at patient satisfaction scores about their treatment when they disclosed the information versus when they chose not to disclose it.
 This will help evaluate the interaction among patient and providers.

o Settings:

- Patients are more likely to share SO/GI information if there are laws that prohibit the providers from denying medical care based upon patient's sexual orientation.
- In the hospital context, both a CMS regulation and Joint Commission standards prohibit discrimination based on sexual orientation (Joint Commission also prohibits discrimination based on gender identity); we need to highlight that a hospital really understands and meaningfully enforces nondiscrimination before starting any SO and GI data collection (and train s all staff about the policy)
- Patients are more likely to be comfortable in LGBT friendly healthcare settings, if the providers
 identify themselves as LGBT friendly provider (for example- wearing a badge to show that you
 are LBGT friendly).
- Need to highlight that a hospital really understands and meaningfully enforces on discrimination before starting any SO/GI data collection.

- Fear of discrimination overshadows the medical relevance in patients in some cases. Patients might be concerned that they might be denied of care if they disclose their So/GI information.
- o Privacy and Confidentiality:
 - Giving the information depends on who is asking and in what setting the information is being asked.
 - However the data is asked, it is important that the data reached the provider.
 - We need to assure that data is being asked always "on need to know" basis and only to support and improve healthcare.
 - Older patients might be fearful that SO/GI will be tied to them in a state system
 that then brings the potential for state based institutional discrimination (because
 many older adults have had a lifetime of institutional discrim, so they are fearful of how that info s
 tays with them).

SO/GI Collection Methods

- o Have any participants responded that they'd be offended by the collection of SOGI?
 - A select few felt that it was offensive to routinely collect this information. However, even this group agreed that if the information is medically relevant it should be collected.
 - "People should not be asked these questions more than once. Once they provide this information, it should be in their records"
 - Also curious if the physicians who were asked about collection of SO/GI thought about it in a larger perspective or in an episodic manner?
 - Do people ask about how others will know the patient's preferred name?
 - If you are asking relevance of SO/GI are you including behavioral healthcare should include that more likely to see the relevance of coming out when regard
- o Explaining to the staff why collecting this data is important is crucial
 - "That goes back to the need for training for staff so that they feel comfortable in posing the question and handling questions from the patients."
 - This goes back to the provider-patient disconcordance in that providers believe that it's best to "treat all patients the same" when they're not all the same.
 - Explaining to the staff why collecting this data is important is crucial
- o Nurses Collecting the data:
 - Nurses feel like they would have time to collect SO and GI.
 - Important for the transgender clients, should be addressed by their gender advocate for the nurse to collection
- Physicians
 - Physicians would put this information in the chart in variable places, worried that it would be lost in the chart
- o Registrars
 - concerns about privacy with registratars can also be addressed with structural changes in patient flow,
 etc
 - if you wait for the doctor the visit is almost over
- o Kiosk might be the way to collect information in future, think about the comparison of verbal vs. electronic
 - Every innovation in care is always met with the push back on workflow and time: tobacco screen,
 SBIRT, depession screen, HIV testing...and it usually is not as onerous
 - Agree that Use of patient input into an electronic device is the future and people are a lot more honest in the studies on that
 - Will Hopkins in the future asked about sexual orientations & gender identity on my charts?

- I would not dismiss technology solutions such as electronic registration/data collection that might not be available now at Johns Hopkins but may be better solutions in the future patient input into an electronic device is the future and people are a lot more honest in the studies on that
- Puts the patient at ease if patients can out information

National Surveys

- O Suggestion: remove "original" from question about sex on birth certificate, and to say "what sex were you assigned at birth", though some may not understand the use of the word "assigned"
 - Team will continue pilot testing on this
 - Majority vote: No consensus
- Suggestion: change wording "check all that apply" to the race question, rather than the "multiracial" response option
 - Consideration of drop down menus for further clarification of racial categories (i.e. Asian→Drop down→ Indian, Chinese, Filipino, Japanese, Thai, Cambodian, Pakistani)
 - Majority vote: Include drop down menus
- o Suggestion: remove "current" from gender identity question
 - Reasoning is the fluidity of the identity
 - Current vote: Remove
- o Suggestion: remove asking about sexual history in last 12 months
 - Reasoning is to compare/contrast LGBTQ identity and sexual health behavior
 - Majority vote: Remove completely or expand greatly
- Suggestion: clarification on experiences in health care, LGBTQ sensitivity, etc. as adult patients
 - Perhaps ask if they have EVER had, and then a timeframe of when it occurred
 - Majority vote: EVER, along with subsequent time when it occurred
- o Comments about provider survey:
 - Suggestion: questions about setting in which doctors work, and also general sentiment about how prepared colleagues are in addressing LGBTQ issues
 - Non-clinical colleagues (culture) should be included
 - ❖ Also, distinctions of clinical colleagues vs. non-clinical
 - * "inclusive and sensitive" is ambiguous wording, Joint Commission field guide could be used, review of non-discriminatory policies including SO/GI information

SO/GI Collection Methods for Trial

- o "Best" Method
 - SAB Member 1 noted that there may be no "single best way" to ask. Some patients are comfortable with being asked verbally in-person and others are not. We must come up with a patient-centered approach. Another challenge to implementation is the age differences in the workforce. There is an older generation that is not trained to have these conversations.
 - SAB Members 2 & 3 agree with SAB Member 1. Some institutions accomplish this by using patient portals to collect information prior to patient appointment.
 - SAB Member 4 suggests that a good way to increase provider competence is to ask about SO/GI through standard scripted language.

Feasibility in the ED

- SAB Member 5: Paper forms are difficult to use in the ED. It is unrealistic for an ED nurse or physician to use a paper form.
- Co-I 1: Paper forms are very challenging; at best, may have a pilot form that will be later be
 converted to electronic. We'll have to be aware of operational challenges when choosing methods
 for implementation.

o General Comments

- Co-I 2: Agrees that we must consider feasibility. There is incredible discordance in these data when collected at multiple points and via multiple methods.
- SAB Member 6: The quantitative survey answers don't uncover the reason why participants answer as they do. Look at intersectionality as it related to responses. It also depends on location and context. A lot of places are already ahead of the curve by asking in different ways and settings; the only way we'll find out the best way to do it is by actually doing it. We've got to find a way to do it electronically. People may feel safer with paper because they can throw it away themselves, but this may be an indicator of a larger fear and insecurity with identity. It's not so much what we're asking, it's *how* we're asking. Providers that ask in a very engaging, normalizing way will get a response without difficulty.
- Co-I 3: Note that about 90% of respondents would be willing to provide SO overall. He suggests the possibility of a structure tiered method rather than a single best method. We need to make sure everyone who is willing to provide the information is able to provide it in the way they feel most comfortable.

eFigure. Study Design

Phase	Procedure	Products		
Qualitative In-Depth Interview Guide Development	Develop interview questions and obtain Stakeholder Advisory Board (SAB) feedback	In-depth interview guide		
Patient Provider Interviews n = 53 n = 26	Individual in-depth interviews with participants until the point of saturation was reached	Interview transcripts		
Qualitative Data Analysis Qualitative Data Analysis	Coding and thematic analysis using Atlas.ti	Codes and themes		
Qualitative Data Results	SAB feedback on qualitative data	Qualitative thematic content report		
Quantitative Survey Development	SAB feedback on quantitative survey questions	 Patient and provider surveys 		
Quantitative Data Collection	 Population-based cross- sectional survey of patients and providers 	Numeric data		
Patient Surveys n = 1516 Quantitative Provider Surveys n = 429 Quantitative	Data analysis	Descriptive statistics		
Data Analysis Data Analysis	(frequencies, percent, bivariate) • Stata Version 13			
Overall Findings and Interpretation	 Interpretation and explanation of the Quantitative and Qualitative Results 	DiscussionImplicationsFuture Research		

eTable 1. Patient and Provider Interview Recruitment

Recruitment Procedures	Patients	Providers		
Interview Recruitment	 Community Organizations, n = 39 (37.5%) Flyers, n = 28 (26.9%) Social Media, n = 5 (4.8%) Word of Mouth, n = 14 (13.5%) No information, n = 18 (17.3%) Total, n = 104 	• E-mail, n = 43 (100%)		
Interview Screening	• Screened out, n = 42 (40.4%)	 Screened out, n = 16 (37.2%) 		
Interview Scheduling	 Scheduled, n = 53 (51%) Screened but not scheduled, n = 9 (8.3%) 	 Scheduled, n = 26 (60.5%) Screened but not scheduled, n = 1 (2.3%) 		

eTable 2. Preferences for Sexual Orientation Collection Among Patients and Providers, Number (%)

Method	Patients					Providers		
	Lesbian N = 244	Gay N = 289	Bisexual N = 179	Straight N = 804	Total N = 1516	Nurse N = 220	Physician N = 209	Total N = 429
Non-verbal self-	124	144	89 (49.7)	436	793	85	115 (54.9)	200
report	(50.8)	(49.6)		(54.4)	(52.3)	(38.5)		(46.5)
Verbal collection	30 (12.3)	18	7 (3.9)	78 (9.7)	133	15	6 (2.7)	21
by registrar		(6.4)			(8.8)	(6.6)		(4.7)
Verbal collection	20 (8.2)	11	12 (6.7)	46 (5.8)	89	65	19 (9.3)	84
by nurse		(3.8)			(5.9)	(29.6)		(19.7)
Verbal collection	37 (15.2)	83	35 (19.5)	121	276	27	52 (25.1)	79
by doctor		(28.7)		(15.0)	(18.2)	(12.4)		(18.6)
Other/none of	32 (13.1)	32	35 (19.5)	116	215	4 (2.0)	2 (1.0)	6 (1.5)
the above		(11.0)		(14.4)	(14.1)			
Refuse to	1 (0.4)	1 (0.5)	1 (0.6)	7 (0.8)	10	24	15 (7.0)	39
answer/would					(0.7)	(10.9)		(8.9)
not ask								