

Informed consent in sexual and reproductive health (SRH) services: a global scoping review of qualitative studies



Preface

Individuals have the right to autonomous, free, and informed decision-making on matters that affect their sexual and reproductive health (SRH). However, the process of informed consent is complex. We conducted a systematic scoping review of qualitative studies exploring issues related to informed consent for SRH services. We searched five electronic databases, reviewed relevant websites, contacted experts, and conducted secondary reference searching of included articles and related reviews. Out of 7,307 unique citations, 130 studies were included in the review. Studies were most commonly from the USA or the UK, although all regions of the world except the Middle East and North Africa were covered. The most commonly studied SRH issues were antenatal screening (n=34), HIV testing (n=21), maternity care (n=17), and contraceptive services (n=15). Other topics covered by multiple studies were abortion (n=10), human papillomavirus (HPV) vaccination (n=10), newborn screening (n=5), voluntary medical male circumcision (n=3), neonatal care (n=2), and STI testing (n=2). No studies were found on sexual health or intimate partner violence-related services. Twenty-two studies focused on adolescents and six focused on women with disabilities. Key themes included interactions between people involved in the consent process (patients/providers, parents/children, partners) and the process itself (required knowledge, key decision-making moments, and specific approaches and tools). Power differentials and trust in providers were also important. Continued attention to consent as a process and appreciation for the social, cultural, economic, and legal factors that shape this process are critical to realizing individual autonomy in SRH services.

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Introduction

International human rights norms and standards have emphasized the importance of empowerment of individuals' and their ability to exercise autonomy and control over their own decision-making. This includes a right to autonomous, free, and informed decision-making on matters that affect their sexual and reproductive health (SRH). Free and informed decision-making is a crucial component of the human rights related to sexual and reproductive health.[1]

Yet, acting on this right can be complex. A person's sexual and reproductive health is dependent on the ability to make free and informed decisions, which is based on an individual's ability to give free and informed consent. While consent is framed as an individual choice, a person's capacity to consent, and the actions they can consent to, are constrained or enabled by their social, cultural, and political context including religion, age, sex, and ethnicity. Power is intrinsic to consent. The hierarchies of power between the person whose consent is being sought and the person who is providing the service, or between two or more individuals where consent is sought, shapes whether the individual can consent. Moreover, consent is often a process – and not necessarily a linear one. An additional dimension of consent is the availability of digital technologies that allow data-sharing (including health data) without consent or availability of apps that allow for surveillance and tracking for health and nutrition purposes in cultural contexts that constrain agency and autonomy, particularly for women.

This systematic scoping review synthesizes the qualitative published and grey literature from the public health and social science fields to explore how the process of informed consent for SRH services happens and how consent is experienced in practice in health care settings. Specifically, this review explores 1) how individuals seeking SRH services understand and experience the process of informed consent for care in health care settings; 2) how this process may be different based on sex, age, disability status, and ethnicity; 3) how the process and ability to give informed consent is shaped by social, cultural, economic, and political factors; 4) how health care providers offering SRH services perceive, understand, and practice the process of getting informed consent; and 5) how providers' willingness, perceptions, and ability to engage in the process of obtaining consent is shaped by their socio-cultural and economic context including laws, policies, and institutional environment of health facilities.

Methods

We conducted a systematic scoping review of the literature following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines for Scoping Reviews (PRISMA-ScR)[2] and the Cochrane Handbook[3].

Inclusion/exclusion criteria

To be included in the review, an article had to 1) be published in a peer-reviewed journal or in the grey literature prior to the search date of 1 August 2019, 2) present primary qualitative data (from interviews, focus groups, observation, etc.) about informed consent for SRH services, including ways in which an individual's informed consent in relation to SRH services may be facilitated or hindered, and 3) study a population seeking or providing SRH services in clinical (health care) settings. Specific population groups of interest included women (married or unmarried), adolescents (boys and girls), and people with disabilities.

Articles were excluded if they focused on consent for research studies (instead of services), presented data collected through quantitative (e.g. surveys) rather than qualitative research methods, or did not present primary data, but rather were think or opinion pieces examining the ethical, political, or social ramifications about informed consent (e.g. Agrawal et al.[4] and Behmer Hansen et al.[5]). Articles providing guidance for informed consent were also excluded.

No restrictions were placed based on location of the intervention. No language restrictions were used on the search.

Search strategy

Five electronic databases were searched on 1 August 2019: PubMed, CINAHL, EMBASE, PsycINFO, and Sociological Abstracts. The complete list of search terms for one database (PubMed) is listed in Appendix 1. This search strategy was adapted to the controlled vocabulary and search functions of each database.

For grey literature, we searched for reports on informed consent on websites of organizations that conduct research on SRH services and human rights. Specifically, we searched the websites of Coram International (www.coraminternational.org), the Guttmacher Institute (www.guttmacher.org), the International Center for Research on Women (www.icrw.org), the International Planned Parenthood Federation (www.ippf.org), and the International Women's Health Coalition (www.iwhc.org).

Selected experts in the field were contacted to identify additional articles not identified through other search methods. Secondary reference searching was conducted on all studies included in the review. This process was iterated until no new studies were identified.

Screening abstracts

Titles, abstracts, citation information, and descriptor terms of citations identified through the search strategy were screened by a member of the study team. Full text articles were obtained of all selected abstracts, and two independent reviewers assessed all full-text articles for eligibility to determine final study selection. Differences were resolved through consensus.

Data extraction and analysis

Data were extracted independently by two reviewers using standardized data extraction forms including fields for study identification, location, population, methods, SRH service, population receiving SRH service, findings, and key themes. Differences in data extraction were resolved through consensus and referral to a senior study team member when necessary. Data were analyzed according to coding categories and outcomes and summarized thematically. We present findings stratified by type of SRH service, according to the five World Health Organization (WHO) SRH focus areas: promoting sexual health, combating sexually transmitted infections (STIs), eliminating unsafe abortion, providing high quality services for family planning, and improving antenatal, delivery, postpartum and newborn care.

Results

Search results

Results from the search and screening process are depicted in Figure 1. Our electronic database search yielded 9,906 initial citations. In addition, from searching websites for grey literature, secondary searching, and contacting experts, we identified 257 unique potential citations. After removing duplicates, we had 7,307 unique citations for screening. After the first level of screening based on title and abstract, we excluded 6,875 citations. Second-level screening of the remaining 247 citations yielded 181 articles for full-text review. Ultimately, 130 studies met the inclusion criteria for this review.[6-135]

Description of studies

Table 1 provides a summary of study characteristics. Studies were published between 1983 and 2019, although there was a heavier concentration of studies in more recent years. Nearly all studies (n=104) collected data through interviews (usually in-depth semi-structured interviews). Of these, 12 also conducted focus groups, eight also conducted observations, and two used three qualitative methodologies. Of the remaining studies, 16 used focus groups alone, while eight used observation alone (generally, observation of provider-patient interactions). Two studies applied qualitative analytical methods to open-ended survey questions, and two used Q-methodology.

About half of the studies took place in either the United Kingdom (UK) (n=38) or the United States (USA) (n=28). Additional regions well represented were sub-Saharan Africa (n=25) and East Asia/Western Pacific (n=13). The remaining studies were conducted in Canada (n=5), Latin America/Caribbean (n=5), and elsewhere in Europe (n=11). No studies were found from the Middle East and North Africa. Studies primarily were conducted in high-income countries (n=94) as classified by the World Bank, with 8 taking place in upper-middle, 17 in lower-middle, and 10 in low-income countries.

While most studies included the end-user (client or patient) population as participants (75% of the 130 included studies), 44 studies included providers, 10 included partners, 15 included parents, guardians, caregivers, or other family members, and 6 included other stakeholders (such as policymakers).

Twenty-two studies focused on issues related to informed consent for adolescents. Six studies focused on issues related to women with disabilities.

The most commonly studied SRH services were antenatal screening (n=33), HIV testing (n=21, 6 in the context of antenatal care), maternity care (n=17), and contraceptive services (n=15, 5 related to hysterectomy/female sterilization). The next most common issues were abortion (n=10), human papillomavirus (HPV) vaccination (n=10), newborn screening (n=6), voluntary medical male circumcision (n=3), neonatal care (n=2), and STI testing (n=2). Other topics such as HIV/STI partner notification, neonatal circumcision, pregnancy testing, infertility, surrogacy, post-rape care, herpes (HSV-2) testing, and mammography screening were covered by one study each.

Specific details about included studies are presented in Table 2, while key findings from each study are presented in Appendix 2.

Below, we present the findings from the included studies organized by WHO SRH focus area, then by specific SRH services. Where possible, we separate findings for specific subgroups within each topic – generally, adolescents and women with disabilities.

Promoting sexual health

No studies focused on informed consent in the context of promoting sexual health.

Combating STIs

HIV testing

Informed consent for HIV testing was explored in 21 studies.[6,17,21,25,31,33,38,48,53,65,70-72,79,83,86-88,97,104,131]

Several of these focused on opt-out or provider-initiated HIV testing.[31,33,48,83,97,104]

While levels of support varied across studies, most of these studies found that opt-out screening was an acceptable approach to HIV testing for public health reasons, although there were some concerns about whether consent was still voluntary and whether adequate counseling was given. Some veterans in the USA thought that HIV testing should be routine (which may reduce stigma and HIV exceptionalism), though they "wished to be asked if they would like to have an HIV test, rather than be told they were going to be" and shared that consent forms were "anxiety-provoking, intimidating and sometimes difficult to understand because of the dense legalistic language" thus increasing reservations about consenting to testing.[25]

One study from Kenya focused on informed consent for HIV testing among adolescents.[131] Adolescents, caregivers, and providers all recognized tensions around adolescent autonomy in the absence of clear consent guidelines. Adolescents valued support people during testing but wanted autonomy over testing and disclosure decisions. Providers felt pressured to defer consent to caregivers, while caregivers wanted to know results regardless of adolescents' wishes.

Six studies focused on HIV testing in the context of antenatal care.[6,17,21,31,53,87] Two studies in rural Malawi[6,17] and one in India[87] found that HIV testing during antenatal care was perceived as compulsory with no allowance for patient autonomy; however, though many believed antenatal testing was more important than choice, some women chose to use traditional birth attendants to "escape what they perceived to be a mandatory testing requirement", and husbands' consent played a major role. In the UK and Canada, maternal HIV testing was generally seen as routine, though some women wanted to give explicit consent prior to testing and felt pressured to accept testing against their will.[21,31,53]

Voluntary medical male circumcision

Three studies, all conducted by the same study team in both Zambia and Swaziland, examined informed consent for voluntary adult medical male circumcision.[67,112,113] Some clients equated written informed consent with releasing the clinic from liability.[113] Most clients felt well prepared for the procedure, although many were surprised by the level of pain experienced during anesthesia and post-surgery.[113] There was some confusion between "risk" of adverse surgical outcomes and reduced "risk" of HIV, a key aspect of understanding informed consent for the procedure.[67] Clients were highly motivated to adhere to wound care, but some were overwhelmed by extensive instructions.[113] Key opinion leaders indicated that informed consent is not well understood in poorly educated communities. Adolescents described barriers to accessing follow-up care and the need for support in overcoming adult gatekeepers,[113] and informed consent procedures for minors were poorly understood and inconsistently implemented at clinic sites.[112]

HIV/STI partner notification

One study from Barbados examined HIV and STI partner notification.[8] Provider referral was sometimes described as "a total suspension of rights" while contract referral took into account that "people need a little gentle pressure sometimes".

STI testing

Two studies explored consent for STI testing.[18,68] In Kenya, adolescent females were concerned that parental notification or stigmatization from parents, family members, or the general community would bar them from accessing services.[18] In Canada, participants reported that the informed consent page at the beginning of an internet-based STI screening website was important for the protection of both the individual and the organization providing the service, as well as legal requirements, though previous experience with in-person informed consent improved users' understanding of the online consent process.[68]

Herpes testing

One study explored informed consent for HSV-2 testing among adolescents in Botswana from the parents' perspective.[39] Parents were generally supportive of testing, but some were concerned about returning test results to only the adolescents though others were supportive of giving privacy/autonomy to their youth and preventing stigmatization.

HPV vaccination

Ten studies, all in high-income countries (Australia, Sweden, UK, and USA), looked at informed consent around HPV vaccination;[14,20,26,29,32,40,69,115,131,133] all but one[32] focused on the adolescent population and how parents, providers, and schools played a role in accessing and consenting for vaccination. Parents expressed a variety of views, ranging from support for adolescent autonomy (to encourage responsible behavior, to protect children from stigma, and to respect confidentiality/privacy/individual rights) to insistence on involvement in decision-making (citing parental rights and a respect for cultural/moral values), though some wanted clearer legal definitions (i.e. age guidelines). School nurses were "convinced" that parental consent for HPV vaccination of girls was necessary, especially for younger age groups who were not "Gillick competent", so would dialogue and negotiate with parents to gain consent to vaccinate, though some schools requested or encouraged student consent as well.[115]

Eliminating unsafe abortion

Ten studies explored informed consent regarding abortion.[16,30,42,45,73,82,106-108,120] In the UK, participants described having to attend mandatory counselling for abortion despite being certain about their decision; they preferred to decline counselling and instead discuss with known/trusted people.[30] Clinicians in France described their job in abortion services as transferring information.[82] However, though providers all agreed the ideal was to respect the couple's autonomy, many found it hard to implement in practice, feeling the need to guide couples in decision-making.

Two studies in Kenya and Nigeria described issues with informed consent for abortion when the male partner was the primary decision-maker.[106,108] Men could pressure their female partners to terminate the pregnancy (directly or indirectly), and sometimes arranged for abortion without the woman's consent. Among women living with HIV in Zimbabwe, men expressed having control over abortion but had limited actual involvement in decision-making; if the woman decided to have an abortion, then she could do it secretly without her partner's consent.[42]

Adolescents faced several barriers to informed consent for abortion.[16,45,107,120] Definitions of legal competence for abortion varied by country, young people often had little information about abortion methods/procedures, and providers had varying expectations for informed consent and adult accompaniment (e.g. should there be an adult, what is the relationship between the adult and the adolescent).

A case study in the UK from the 1980s explored the mental capacity of a girl with intellectual disabilities to give consent to abortion: providers believed abortion was in her best interest, her caregivers were opposed, but the girl seemed unable/unwilling to make a decision or give consent.[73]

Providing high quality services for family planning

Pregnancy testing

One study from Tanzania[49] documented widespread coerced and forced pregnancy testing in schools, leading to exclusion and expulsion of pregnant students, although this is not supported by Tanzanian law. Coercive testing was problematic: since pregnancy testing was a required precondition for admission to school, consent was not voluntarily or freely given. Although a student could technically refuse to undergo a pregnancy test, doing so would often leave her with no meaningful educational options.

Contraceptive services overall

Providers sometimes act as gatekeepers to contraceptive services, using various strategies to counsel women about contraceptive methods and gain informed consent.[27,34,37,43,55,58,78,91,109,110,116,118,128,134,135] In India, providers placed high value on partner consent to contraceptive use; doctors, nurses, midwives, and traditional birth attendants restricted access to long-acting/permanent contraceptive methods based on partner consent more than they restricted short-term methods like condoms or pills.³⁴

In the USA, some women perceived pressure from providers to choose a contraceptive method during post-abortion care. Those who were presented a range of options with relevant pros and cons "felt better equipped" to make a decision with self-efficacy and autonomy.[27] Providers noted that not all abortion patients want contraceptive care and that they didn't want to coerce or shame their patients; however, they found it hard to balance who to target for counselling and how much information to provide in order to go through both the full informed consent process as well as the abortion appointment.[78]

Women with disabilities reported that other people such as family members or providers made key decisions about starting to use contraceptives and which method to use.[91,110]

Female sterilization/hysterectomy

One study from Scotland examined how informed consent guidance should be applied to decisions between variant surgical procedures, such as abdominal or vaginal hysterectomy.[58] Interviews with women and providers suggested that gynaecologists generally offered little opportunity for patients to influence which surgical procedure was selected. While women did not express a desire for a greater say in this selection, they appreciated being told, or would have liked to know, why particular procedures were recommended. In contrast, one study in the United States found that women saw their physician as an information provider and recommendation-giver and would like to have a second opinion before making the decision to proceed with hysterectomy. Most physicians seemed willing to defer to a woman's choice to not have a recommended hysterectomy, but would not perform a hysterectomy at the woman's request if they thought it unnecessary. [109]

In South Africa, women living with HIV reported being sterilized without their informed consent or without their knowledge, describing healthcare providers' failure to respect their autonomy, lack of information about what sterilization entailed, and subtle or overt pressure to sign the consent form.[116]

Two studies focused on hysterectomies for women with disabilities. In Taiwan, decision-making for tubal ligation for women with intellectual disabilities living with their families was done solely by the families and health professionals, rarely involving the women themselves; some were not even informed of the nature of the surgery.[43] Similarly, in Mexico, women with disabilities reported coercive or forced sterilization and abuse when visiting gynecologists.[110]

Improving antenatal, delivery, postpartum and newborn care

Informed consent around maternal and newborn health were the most commonly explored topics.

Antenatal screening

Informed consent for antenatal screening, generally for genetic abnormalities like Down Syndrome and β -thalassaemia, was the most commonly studied issue.[10-13,15,19,41,46,47,51,59-63,66,74,80,84,85,89,90, 98,99,103,105,111,121-124,127,129,130]

While participants across these studies generally wished to be actively involved in testing decisions, multiple uncertainties in the process and timing, feeling hurried or anxious, and lack of knowledge and understanding about biological processes and test implications made this difficult. While some women described receiving advice or having non-directive discussions with health professionals, others perceived testing as routine, felt pressured to accept it, or simply did not know they were free to choose whether or not to have the tests. Generally, both clients and health professionals preferred for providers to give information and support for informed decision-making.

Men and partners of pregnant women often reported that they did "mediation" and shared/collaborative decision-making in antenatal screening, and that their engagement with health professionals was usually determined by the preferences and choices of the pregnant woman.[11,61,111,127,129,130] One study noted the impact of antenatal screening for Down Syndrome on the disabled community and stigma for women who decline testing.[85] One study from the UK noted that women discussed "information" and "consent" as two separate issues, thus challenging assumptions around the term informed consent.[13]

Maternity care

Seventeen studies explored informed consent in the context of maternity care,[7,9,22-24,44,77,81,92-96, 101,114,117,125] often contrasting the power and information dynamics between patients and providers. One study's authors reflected that "[i]nformed consent is an oft-cited human right in health care, yet in maternity care the micro-politics of how informed consent is gained is difficult to ascertain, leading to a situation whereby the concept of informed consent is more robust than the reality of practice; an illusion of informed consent exists, yet information is often biased towards medicalized birth practices", [95] drawing from examples of consenting for epidural in labor or using water for labor/birth when little evidence-based information was given and women needed to make high-risk decisions under time constraint. Describing women's accommodation of their health providers, another study used the term "informed compliance" in lieu of "informed consent".[114]

Three studies explored informed consent around mode of delivery (caesarean section vs vaginal delivery).[7, 81,92] Interestingly, "women did not have autonomous choice over their actual birth method, but neither did they necessarily want it"[81] – women expressed the desire to be involved in decision-making but not all were confident or actively participated in decision-making. Women acknowledged that the decision of mode of delivery cannot be static or final because medical/social circumstances may change and stated that concern over their baby's or their own health took precedence over personal preference. In Somalia, the choice of vaginal delivery or c-section sometimes depended on permission from extended family members.[7] In the UK and USA, induction of labor was often done with poor informed consent: minimal informative was given by providers, who usually presented induction as the preferred option and rarely discussed alternative care plans or the relative risk of induction versus continued pregnancy.[77,93] However, women typically trusted their providers' judgment and rationale so complied with induction despite lack of informed decision-making.

One UK study found that expectant fathers played a key persuasive role in deciding the place of birth, though generally hospital births were seen as the "norm" and a means of protection among trusted healthcare providers; male partners gave the opinion that disrupting the "status quo" was unjustified.[22] A phenomenological study among women with disabilities in Ireland found that they felt that they lacked ability to make choices and maintain control over their childbirth experiences, since the "usual services" were geared toward "normal" able-bodied women, not adapted for their individual needs.[125] Some women with disabilities mentioned that they were offered pregnancy termination; though they all refused, they felt subsequent pressure to put their newborn babies in the care of social services.

Newborn screening

Five studies from the Netherlands, UK, and US found fairly similar perceptions around newborn screening.[35, 36,50,57,102] Information giving about newborn screening was sometimes reported to be ad hoc, with most women receiving information in the postnatal period. Mothers talked about newborn screening as a routine procedure that "had" to be done, though they generally wanted information about it to be able to consent. Consent for screening was often compromised because tests were being offered by a trusted health professional and there was a social expectation that responsible mothers should have their babies tested.

Neonatal care

Two studies in the Netherlands and Norway explored informed consent in neonatal care.[28,56] Parents often deferred decision-making to providers, giving responsibility to those who had the "necessary medical knowledge and experience" to make the best rational decisions about infant care under time pressure. NICU providers stated their preference for prospective consent but acknowledged the need for deferred consent; though the latter sometimes prompted ethical concerns over parental autonomy, in practice, deferred consent worked well assuming good communication and timing of approach to parents.

Neonatal circumcision

One study on neonatal circumcision from the USA found that a shared decision-making tool helped providers with conversations with clients.[64] Prior to the introduction of the tool, clinicians used a consent document to frame circumcision as a default practice. Using the tool conferred agency to both parents and clinicians, and it facilitated shared decision-making. Clinicians reported recognizing the tool's positive effect on their communication process.

Infertility

One study looked at infertility issues for male adolescents undergoing cancer treatment in the USA.[52] Although physicians and parents agreed that infertility would have a major impact on future quality of life, they sometimes disagreed on whether the topic should be discussed with adolescents. Physicians always wanted a separate discussion with adolescents because of the sensitive nature and the experience that parents sometimes misjudged the stage of maturity of their son. Parents, however, wanted control over whether physicians discussed the topic with their child and what was said. Physicians did not accept this control and, when necessary, would bypass the parents and discuss the topic with the adolescent even when parents refused consent.

Surrogacy

One study examined informed consent for surrogate mothers in India.[119] None of the 14 surrogate mothers interviewed were able to explain the risks involved in embryo transfer and fetal reduction. The study also found that most doctors made unilateral decisions about embryo transfer and fetal reduction, while the commissioning parents were usually only indirectly involved. Key themes included difficulties in explaining procedures, autonomy, self-payment of fertility treatment, and conflicts of interest.

Post-rape care

One study from Kenya found multiple violations of the rights of two sexually abused adolescent girls.[126] Providers showed little regard for informed assent, confidentiality, and privacy while offering post-rape care.

Mammography screening

In Norway, women expressed gratitude at being called in for mammography screening, which made the decision-making process to get screened for breast cancer easier since others had taken control to make the decision to take action for them.[100]

Discussion

In this scoping review, we identified a wide range of studies that qualitatively examined informed consent issues in SRH services. Studies were relatively diverse in terms of topics, populations, and geographic regions. However, while there was a substantial amount of research on some topics, such as antenatal screening, HIV testing, and maternity care, other topics had little to no research. In particular, we noted sexual health and intimate partner violence services as two areas with major literature gaps. Most studies used individual interviews, perhaps a natural choice when seeking to gain in-depth information about a sensitive and complex topic such as experiences with informed consent.

In our findings, we identified two broad themes that seemed to come up across studies: who is involved in decisions around informed consent and how the informed consent process unfurls.

The first theme focused on interactions between people involved in the consent process, including clients and providers, caregivers and adolescents, and women and their partners. First, several studies described issues around the dynamic nature of control and communication between clients and providers – how decisions are presented to patients, how clients respond, and how providers can shape those decisions, such as through opt-in or opt-out policies. In particular, the issue of trust in patient-provider relationships was important. Second, several studies examined SRH decisions faced by adolescents and discussed the role of caregivers in making these decisions either with or on behalf of the adolescents. Third, several studies discussed the role of sexual partners, particularly husbands and partners of women, as many of the SRH issues covered were experienced predominantly by women.

These issues often arose in the context of unequal gender norms and gender power structures. Within this set of studies, several articles looked at barriers to communication across these groups, such as language barriers, stigma, and social norms. Importantly, several studies highlighted situations where individuals were denied appropriate autonomy and decision-making power over their own SRH decisions, such as with mandatory pregnancy testing and expulsion of pregnant students in Tanzanian schools.[49] As expected, these interpersonal dynamics around who makes consent decisions particularly affected populations with reduced autonomy, such as adolescents or women with disabilities. Finally, several studies noted that decisions are not made by one person or another in these dyads, but rather there are continuums of influence over decision-making, capacity to consent, and micro-politics about how power is exerted in conversations and decision-making processes. These studies highlight the need to recognize and explicitly consider how existing power differentials play out in informed consent processes; for example, one study suggested that in some cases, seeing autonomy as relational might open space for a dialogical approach towards obtaining informed consent.[69]

The second major theme across studies was issues related to the informed consent process itself. First, several studies considered the knowledge needed to make a truly informed decision, as well as the timing and manner of presentation of this information. On a related note, they considered local cultural norms that may shape assumptions about how to share this knowledge and what knowledge matters in informed consent. Second, several studies broke down the process of informed consent and covered key moments in decision-making, emphasizing consent as a process rather than a one-off event.

Finally, another set of studies described specific contexts, approaches, and tools that could shape the consent process. For example, some studies examined the differences between online and in-person consent, [68] while others examined tools such as the option grid tool[64] that could improve communication and affect how consent was experienced.

Our findings from this scoping review must be considered in light of its strengths and weaknesses. We used a thorough and systematic search process and identified a large number of articles across a range of topics.

However, it was sometimes difficult to decide whether a given study was discussing informed consent or not, and we thus may have missed some studies that could have been relevant or included some studies that others would have excluded. We noted several topics that were difficult to disentangle from informed consent and thus difficult to make inclusion decisions on. First, several articles talked about decision-making processes for different SRH services; we did not consider this to always be related to informed consent. For example, friends and family members may influence decision-making or may be consulted prior to the decision, but this does not necessarily signal a problem with informed consent. Similarly, privacy and confidentiality were often related to informed consent, but again we did not consider studies looking at confidentiality to always be relevant to informed consent. For example, adolescents may be concerned about privacy of their decisions, but this is not necessarily related to informed consent. Similarly, it was sometimes difficult to separate informed consent from access to SRH services. For example, Wanyenze and colleagues looked at barriers to using SRH services,[136] which included concerns about privacy and relationships with providers, but did not clearly describe issues with informed consent. Finally, our search was conducted in 2019, and our review included studies that collected data back to the 1980s. Perceptions of informed consent may change over time.

Conclusion

In summary, the process of informed consent differs widely across diverse SRH services and settings. Common themes of power and decision-making in who is involved with the consent process and how the process occurs showed the complexities of informed consent in different context. While there is a significant evidence base of qualitative studies examining how the informed consent process is experienced globally, these studies primarily come from high-income countries and are unevenly distributed across SRH service delivery areas, leaving gaps in the literature that should be filled by future studies. In practice, continued attention to consent as a process and appreciation for the social, cultural, economic, and legal factors that shape this process is critical to realizing individual autonomy in SRH services.

Figure 1: PRISMA flowchart showing the disposition of citations through the search and screening process

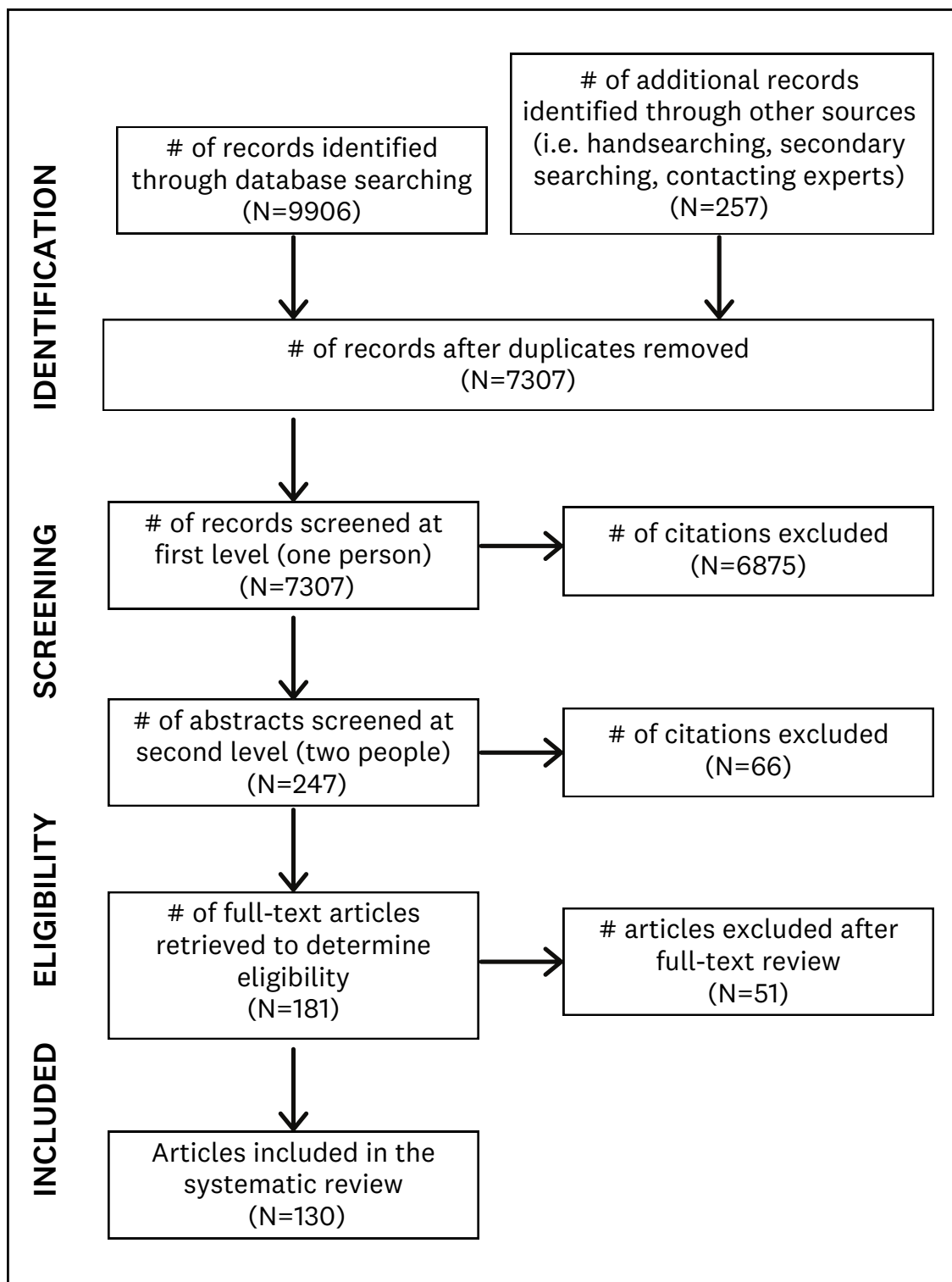


Table 1. Summary of study characteristics

Characteristic	# of studies
Qualitative methodology	
Interviews (usually in-depth semi-structured)	104
Focus group discussions	29
Observations	18
Other (e.g. qualitative analysis of open-ended survey questions, Q-methodology)	5
Location by region	
AFRO: Benin, Botswana, Burkina Faso, Ethiopia, Ghana, Kenya, Malawi, Mali, Nigeria, Rwanda, Somalia, South Africa, Swaziland, Tanzania, Uganda, Zambia, Zimbabwe	25
EURO: Finland, France, the Netherlands, Norway, Sweden, United Kingdom	49
PAHO: Barbados, Brazil, Canada, Mexico, United States of America	38
SEARO: Bangladesh, India, Pakistan	6
WPRO: Australia, Hong Kong, Japan, Malaysia, New Zealand, Taiwan	12
Location by income classification	
High-income	94
Upper-middle income	8
Lower-middle income	17
Low-income	10

Study participants	
End-user	97
Providers	44
Partners	10
Parents/guardians/caregivers/other family members	15
Other stakeholders (e.g. policymakers)	6
Special populations	
Adolescents	22
Women with disabilities	6
WHO SRH focus areas	
Promoting sexual health	0
Combating STIs	38
Eliminating unsafe abortion	10
Providing high quality family planning services	16
Improving antenatal,delivery, postpartum, and newborn care	63

Note: some studies overlapped in study characteristics, so total numbers within each category do not add to 130.

Table 1. Summary of study characteristics

SRH services	Citation ID	Location	Study participants	Population for SRH services	Methods
Abortion	Ambuel, 1992	USA	Adolescent women (13-21 years)	Adolescent females (13-21 years)	Interviews
Abortion	Brown, 2013	UK: North England	Women (1-20 years, waiting for or recently had abortion)	Women (pregnant)	Interviews
Abortion	Clyde, 2013	Mexico: Mexico City	Health professionals, adolescent girls (12-17 years)	Adolescent females (12-17 years)	Interviews and observation
Abortion	Higgs, 1983	UK: England: London	Women with disabilities (pregnant), providers	Women with disabilities (pregnant)	Interviews
Abortion	Rhenstrom Loi, 2018	Kenya: Kisumu	Women (19-32 years, previous abortion)	Women	Interviews
Abortion	Tatum, 2012	Mexico: Mexico City	Adolescent girls (13-17 years with middle-, lower-middle, and lower-income)	Adolescent females (unwanted pregnancy)	Interviews and focus groups
Abortion (HIV)	Chibango, 2018	Zimbabwe: Gokwe North District, Midlands Province	People living with HIV and their partners	Women living with HIV (pregnant)	Focus groups
Abortion (selective terminations)	Legendre, 2009	France: Paris	Providers (obyn)	Women (pregnant)	Interviews
Abortion/family planning	Princewill, 2017	Nigeria	Women	Women	Interviews
Abortion/family planning	Rashid, 2011	Bangladesh: Phulbari	Adolescent women (married)	Adolescent females	Interviews
Antenatal screening	Ahmed, 2013	UK: Yorkshire and Humber	Women (midwives)	Women (pregnant)	Interviews
Antenatal screening	Ahmed, 2014	UK	Women	Women (pregnant)	Interviews
Antenatal screening	Al-Jader, 2000	UK: South Wales	Women (pregnant)	Women (pregnant)	Interviews
Antenatal screening	Barr, 2013	UK: England	Women (pregnant)/their partners, health professionals	Women (pregnant)	Focus groups
Antenatal screening	de Jong, 2013	Netherlands	Women (pregnant), healthcare providers	Women (pregnant)	Focus groups
Antenatal screening	Farsides, 2004	UK: South East England	Providers	Women (pregnant)	Interviews and focus groups
Antenatal screening	Hunt, 2005	USA: Texas	Women (pregnant), providers	Women (pregnant)	Interviews and observation
Antenatal screening	Levy, 1999	UK: England: East Midlands	Women (pregnant)	Women (pregnant)	Observation

Antenatal screening	Ockleford, 2003	UK: England: Leicester	Women (pregnant)	Women (pregnant)	Interviews
Antenatal screening	Oliver, 1996	UK	Women (pregnant), providers (midwives, Itrasonographers)	Women (pregnant)	Interviews
Antenatal screening	Pilnick, 2016	Hong Kong	Women (pregnant, 35-41 years) and providers	Women (pregnant)	Observation
Antenatal screening	Potter, 2008	Canada: Ottawa: Ontario	Women (pregnant)	Women (pregnant)	Interviews
Antenatal screening	Tsianakas, 2002	Australia: Melbourne, Victoria	Women (Muslim, immigrant)	Women (pregnant)	Interviews
Antenatal screening	Williams, 2011	UK: England	Male partners (of pregnant women)	Women (pregnant)	Interviews
Antenatal screening	Farrell, 2014	Canada	Parents, providers	Infants	Interviews
Antenatal screening (Cell-free fetal DNA)	Farrell, 2019	USA: Ohio: Cleveland	Partners of pregnant women	Women (pregnant)	Interviews
Antenatal screening (Down Syndrome)	Chiang, 2006	Taiwan: Taipei	Women (pregnant, 22-35 years)	Women (pregnant)	Interviews and observation
Antenatal screening (Down Syndrome)	Lewis, 2013	UK: England: London, South of England	Women (pregnant)	Women (pregnant)	Interviews
Antenatal screening (Down Syndrome)	Santalathi, 1998	Finland: Jyväskylä and Kuopio	Women (with current pregnancy)	Women (pregnant)	Interviews
Antenatal screening (Down Syndrome)	Tsouroufli, 2011	UK: South East England	Women (with current pregnancy); healthcare providers (midwives and health care assistants)	Women (pregnant)	Observation
Antenatal screening (Down syndrome)	Watterbjork, 2015	Sweden: Orebro County Council	Women (pregnant), partners	Women (pregnant)	Interviews
Antenatal screening (Down Syndrome)	Williams, 2005	UK	Men (with pregnant partners)	Women (pregnant)	Interviews
Antenatal screening (Down Syndrome, sickle cell, thalassaemia)	Ahmed, 2012	UK: large city	Women (pregnant, African, British White, Caribbean, Chinese, Pakistani)	Women (pregnant)	Q-methodology
Antenatal screening (fetal aneuploidy)	van Bruggen, 2018	Netherlands	Women (with current pregnancy)	Women (pregnant)	Interviews
Antenatal screening (fetal testing)	Maridosian, 1990	USA: California	Women (pregnant)	Women (pregnant)	Interviews
Antenatal screening (first trimester aneuploidy/Down Syndrome)	Farrell, 2011	USA: Ohio: Cleveland	Women (pregnant, 18-45 years)	Women (pregnant)	Focus groups
Antenatal screening (maternal alpha-fetoprotein screening)	Markens, 1999	USA: Southern California	Women (pregnant)	Women (pregnant)	Interviews

Antenatal screening (Non-invasive prenatal genetic diagnostic (NIPD))	Kelly, 2012	UK	General population	Women (pregnant)	Q-methodology
Antenatal screening (noninvasive prenatal testing)	Farrell, 2014	USA: Ohio: Cleveland	Women (pregnant, 18-45 years)	Women (pregnant)	Focus groups
Antenatal screening (sickle cell and thalassaemia) in primary care	Tsianakas, 2012	UK: inner city	Women (pregnant)	Women (pregnant)	Interviews
Antenatal screening (thalassaemia carrier testing)	Ahmed, 2005	UK: northern England	Women (pregnant, Pakistani)	Women (pregnant, Pakistani)	Interviews
Antenatal screening (ultrasound)	Firth, 2011	Tanzania	Women (pregnant)	Women (pregnant)	Interviews
Antenatal screening (β -thalassaemia)	Cousens, 2013	Australia: Victoria	Women (pregnant)/their partners	Women (pregnant)	Interviews
Antenatal screening (β -thalassaemia carrier)	Cousens, 2014	Australia: Victoria	Health professionals (obstetricians, general practitioners, midwives, genetic counselors, and hematologists)	Women (pregnant)	Interviews
Circumcision (neonatal)	Fay, 2016	USA: New Hampshire	Parents of male newborns, Providers	Newborn males	Interviews and observation
Circumcision (VMMC)	Friedland, 2013	Zambia: Lusaka; Swaziland	Men (18+ years) and adolescent boys (13-17 years)	Men and adolescent boys	Interviews
Circumcision (VMMC)	Schenk, 2012	Zambia: Lusaka	Adolescent boys (13-17 years), providers, parents/caregivers	Adolescent males	Interviews and focus groups
Circumcision (VMMC)	Schenk, 2014	Zambia and Swaziland	Men and adolescent boys (13-17 years), providers, stakeholders (policymakers)	Men and adolescent boys	Interviews
Contraceptive services	Calhoun, 2013	India: Uttar Pradesh	Providers	Women	Interviews and focus groups
Contraceptive services	Dehlendorf, 2014	USA: California: San Francisco	Women, providers	Women	Observation
Contraceptive services	McCarthy, 2010	UK: England	Women with disabilities, providers (general practitioners)	Women with disabilities	Interviews
Contraceptive services	Stanback, 2001	Ghana: Multiple locations	Providers	Women	Interviews
Contraceptive services	Sundstrom, 2018	USA: Southeastern	Women (postpartum, 18-39 years)	Women (postpartum)	Focus groups

Contraceptive services	Yee, 2011	USA: Illinois: Chicago	Women (postpartum, urban minority, low-income)	Women	Interviews
Contraceptive services (emergency contraception)	Wilkinson, 2014	USA: Nashville, Tennessee; Philadelphia, Pennsylvania; Cleveland, Ohio; Austin, Texas; and Portland, Oregon	Providers (pharmacists)	Adolescent females	Observation
Contraceptive services (immediate postpartum IUD insertion)	Carr, 2018	USA: New Mexico: Albuquerque	Women (postpartum)	Women (postpartum)	Interviews
Contraceptive services (postabortion)	Brandi, 2018	USA: Massachusetts: Boston	Women	Women (pregnant, just had abortion)	Interviews
Contraceptive services (postabortion)	Jerman, 2019	USA: Multiple locations	Providers	Women	Interviews and focus groups
Contraceptive services (sterilization/hysterectomy)	Chou, 2011	Taiwan: Hsinchu	Families with sterilized women with intellectual disabilities	Women with disabilities	Interviews
Contraceptive services (sterilization/hysterectomy)	Entwhistle, 2006	UK: Scotland: North-East	Women, providers	Women	Interviews
Contraceptive services (sterilization/hysterectomy)	Richter, 2002	USA: South Carolina	Women	Women	Focus groups
Contraceptive services (sterilization/hysterectomy)	Rodriguez 2015	Mexico: Mexico City	Women with psychosocial disabilities	Women with disabilities	Interviews
Contraceptive services (sterilization/hysterectomy)	Strode, 2012	South Africa: KwaZulu-Natal, Guateng	Women living with HIV	Women living with HIV	Interviews
HIV testing	Bokhour, 2009	USA: California, New England	Patients and primary care providers	Veterans	Focus groups
HIV testing	Burrage, 2008	USA: Indiana: Indianapolis	Women at community health clinics	Women	Interviews
HIV testing	Cowan, 2013	USA: New York: Bronx	Emergency room patients	General population	Interviews
HIV testing	Groves, 2010	South Africa: Durban	Women (pregnant)	Women (pregnant)	Interviews
HIV testing	Hardon, 2012	Burkina Faso, Kenya, Malawi, Uganda	Women living with HIV, providers	Women (pregnant)	Interviews and focus groups
HIV testing	Heckert, 2001	New Zealand	Women (pregnant)	Women (pregnant)	Interviews
HIV testing	Kedote, 2011	Benin	Women (pregnant)	Women (pregnant)	Interviews
HIV testing	Leidel, 2015	Australia: Perth, Western	Providers	General population	Interviews

HIV testing	MacCarthy, 2014	Brazil: Salvador	Women living with HIV	Women living with HIV (pregnant)	Interviews
HIV testing	Manongi, 2014	Tanzania: Moshi urban and Rongo districts	General population	General population	Focus groups
HIV testing	Noland, 2015	USA	General population	General population	Interviews
HIV testing	Pollard, 2013	UK: Southeast England: Brighton	General population	General population	Focus groups
HIV testing	Wilson, 2017	Kenya: Nairobi	Adolescents, caregivers, providers	Adolescents	Interviews and focus groups
HIV testing (maternal)	Aarnio, 2009	Malawi: Manchogi district	Men (married)	Women (pregnant)	Focus groups
HIV testing (maternal)	Angotti, 2011	Malawi: Mchinji district (interviews), Balaka district (FGDs & observational field journals)	Women (pregnant)	Women (pregnant)	Interviews, focus groups, and observation
HIV testing (maternal)	Baxter, 2000	UK	Women (pregnant)	Women (pregnant)	Interviews
HIV testing (maternal)	Bulman, 2013	Canada: Newfoundland and Labrador	Women (pregnant, 14-35 weeks gestation)	Women (pregnant)	Interviews
HIV testing (maternal)	de Zulueta, 2007	UK: central London	Women (pregnant)	Women (pregnant)	Interviews
HIV testing (maternal)	Madhivanan, 2014	India: Maharashtra: Pune, Karnataka: Mysore	Women living with HIV	Women living with HIV (pregnant)	Interviews
HIV testing and care	Castro-Vasquez, 2007	Japan	Men (Latin American)	Men	Interviews
HIV testing and care	Feyissa, 2012	Ethiopia: Oromia: Jimma	Providers	People living with HIV	Interviews and focus groups
HIV/STI partner notification	Adams, 2015	Barbados	General population, Providers, PLHIV	General population, People living with HIV	Interviews
HPV vaccination	Alexander, 2012	USA: Indiana: Indianapolis	Adolescent males (13-17 years), parents/guardians	Adolescent males (9-26 years)	Interviews
HPV vaccination	Batista Ferrer, 2016	UK: southwest England	Adolescent girls (12-13 years), school staff, providers	Adolescent females (12-13 years)	Interviews and observation
HPV vaccination	Brabin, 2007	UK: Manchester	Parents (of 11-12 year old school children)	Adolescents	Open-ended survey questions
HPV vaccination	Brown, 2010	UK: Hampshire and Wiltshire	Providers (general practitioners and nurses)	Adolescent females (12-13 years)	Interviews
HPV vaccination	Bunton, 2013	Australia	Women	Women	Observation
HPV vaccination	Chang, 2018	USA: New York: New York City	Adolescents (14-17 years), parents	Adolescents	Interviews

HPV vaccination	Gottvall, 2015	Sweden	Providers (nurses)	Adolescent females	Focus groups
HPV vaccination	Stretch, 2009	UK: England: Greater Manchester	Providers (school nurses)	Adolescent females (12-13 years)	Interviews
HPV vaccination	Wilson, 2012	Canada: Ontario	Providers/stakeholders	Adolescent females	Interviews
HPV vaccination	Wood, 2011	UK: Wales	Providers (nurses, GPs), stakeholders	Adolescent females (12-13 years)	Interviews
HSV-2 testing	Cham, 2016	Botswana: urban, peri-urban, and rural communities	Parents (of an adolescent (13-17 years) enrolled in junior secondary school)	Adolescents	Focus groups
Infertility	de Vries, 2009	Netherlands	Providers, parents of male adolescents undergoing cancer treatment	Adolescents	Interviews
Mammography screening	Osterlie, 2008	Norway: Sør- and Nord-Trøndelag	Women	Women	Focus groups
Maternity care	Bluff, 1994	UK: South of England	Women (postpartum)	Women (pregnant)	Interviews
Maternity care	Churchill, 2000	UK: Wales: Powys	Women (3 months postpartum)	Women (pregnant)	Open-ended survey questions
Maternity care	Newnham, 2017	Australia	Women (pregnant), providers (midwives, doctors)	Women (pregnant)	Interviews and observation
Maternity care	Nicholls, 2019	UK: London	Women (pregnant), providers (midwives, obstetricians)	Women (pregnant)	Interviews
Maternity care	Pafs, 2016	Rwanda	Women (who suffered a near-miss event in early or late stage in pregnancy)	Women (pregnant)	Interviews
Maternity care	Stapleton, 2002	UK: Wales	Women (pregnant), health professionals (who provide antenatal care).	Women (pregnant)	Observation
Maternity care	Sumankuuro, 2019	Ghana: Nadowli-Kaleo and Daffiama-Bussie-Issa districts, Upper West Region	Women, providers (doctors, TBAs), and stakeholders	Women (pregnant)	Interviews and focus groups
Maternity care	Walsh-Gallagher, 2012	UK: Ireland	Women with disabilities (pregnant)	Women with disabilities (pregnant)	Interviews
Maternity care (Assisted childbirth)	Ag Ahmed, 2018	Mali: Gossi	Women (nomads)	Women (pregnant, nomads)	Interviews and observation

Maternity care (childbirth decisions)	Nelson, 1983	USA: Vermont	Women (postpartum), providers	Women (pregnant)	Interviews
Maternity care (c-section vs vaginal delivery)	Abdillahi, 2017	Somalia	Women, Providers	Women	Interviews
Maternity care (c-section vs vaginal delivery)	Kingdon, 2009	UK: England: Liverpool	Women (pregnant)	Women (pregnant)	Interviews
Maternity care (c-section vs vaginal delivery)	Moffat, 2007	UK: Scotland: Aberdeen	Women (pregnant, previously had a caesarean section for a nonrecurrent cause)	Women (pregnant)	Interviews, observations, and participant diaries
Maternity care (induction)	Jay, 2018	UK: South of England	Women (pregnant)	Women (pregnant)	Interviews
Maternity care (induction)	Moore, 2014	USA	Women (pregnant, 21+ years)	Women (pregnant)	Interviews
Maternity care (Maternal-fetal surgery for myelomeningocele (MMC) and fetal intervention) for congenital diaphragmatic hernia (CDH).	Blumenthal-Barby, 2016	USA: Southwestern	Women (pregnant, diagnosed with fetal myelomeningocele or congenital diaphragmatic hernia)	Women (pregnant, diagnosed with fetal myelomeningocele or congenital diaphragmatic hernia)	Observation
Maternity care (place of birth)	Bedwell, 2011	UK: North West of England	Men (expectant fathers)	Women (pregnant)	Interviews
Neonatal care	Brinchmann, 2002	Norway	Parents (who had experienced one or more life-and-death decisions relating to their critically ill and/or premature infant)	Infants	Interviews
Neonatal care	Den Boer, 2019	Netherlands, USA	Healthcare providers (NICU staff)	Women (pregnant)	Interviews
Newborn screening	Campbell, 2005	USA: Illinois: Chicago	Parents	Infants	Focus groups
Newborn screening	Detmar, 2007	Netherlands	Parents	Infants	Focus groups
Newborn screening	Cusworth-Aerts, 2007	USA	Parents, healthcare providers	Women (pregnant)	Interviews and focus groups
Newborn screening (PKU, CHT, cystic fibrosis, DMD)	Parsons, 2007	UK: Wales	Women (postpartum)	Women (postpartum)	Interviews
Newborn screening (PKU, DMD)	Campbell, 2003	USA	Parents	Infants	Interviews
Post-rape care	Wangamati, 2016	Kenya: Homa Bay County	Adolescents, caregivers, providers, police	Adolescent females	Interviews and observation
Pregnancy testing	CRR, 2013	Tanzania: Iringa, Kilimanjaro, Pwani, Dar es Salaam, and Morogoro regions	Adolescent girls, healthcare providers	Adolescent females	Interviews

Newborn screening	Detmar, 2007	Netherlands	Parents	Infants	Focus groups
Newborn screening	Cusworth-Aerts, 2007	USA	Parents, healthcare providers	Women (pregnant)	Interviews and focus groups
Newborn screening (PKU, CHT, cystic fibrosis, DMD)	Parsons, 2007	UK: Wales	Women (postpartum)	Women (postpartum)	Interviews
Newborn screening (PKU, DMD)	Campbell, 2003	USA	Parents	Infants	Interviews
Post-rape care	Wangamati, 2016	Kenya: Homa Bay County	Adolescents, caregivers, providers, police	Adolescent females	Interviews and observation
Pregnancy testing	CRR, 2013	Tanzania: Iringa, Kilimanjaro, Pwani, Dar es Salaam, and Morogoro regions	Adolescent girls, healthcare providers	Adolescent females	Interviews

Appendix 1. Search strategy for PubMed

Concept 1: Informed consent

consent[tiab] OR assent[tiab] OR autonomy[tiab] OR confidentiality[tiab] OR "informed consent"[Mesh] OR "parental consent"[Mesh] OR "parental consent"[tiab] OR "third party consent"[Mesh] OR "third party consent"[tiab] OR "informed consent by minors"[Mesh] OR "informed consent by minors"[tiab] OR "parental notification"[Mesh] OR "parental notification"[tiab] OR "proxy"[Mesh] OR "proxy"[tiab]

AND

Concept 2: SRH services

Sexual and Reproductive Health (general)

consent[tiab] OR assent[tiab] OR autonomy[tiab] OR confidentiality[tiab] OR "informed consent"[Mesh] OR "parental consent"[Mesh] OR "parental consent"[tiab] OR "third party consent"[Mesh] OR "third party consent"[tiab] OR "informed consent by minors"[Mesh] OR "informed consent by minors"[tiab] OR "parental notification"[Mesh] OR "parental notification"[tiab] OR "proxy"[Mesh] OR "proxy"[tiab]

Contraception

"reproductive plan"[tiab] OR "reproductive planning"[tiab] OR "reproductive counseling"[tiab] OR "reproductive counselling"[tiab] OR contraception[tiab] OR contraceptive[tiab] OR contraceptives[tiab] OR "contraceptive use"[tiab] OR "birth control"[tiab] OR "birth spacing"[tiab] OR "child spacing"[tiab] OR "Reproductive Health Services"[MeSH] OR "Reproductive Health Services"[tiab] OR "Reproductive Medicine"[MeSH] OR "Contraception"[MeSH] OR "family planning"[tiab] OR "Family Planning Services"[MeSH] OR "family planning service"[tiab] OR "family planning services"[tiab] OR "Family Planning Programs"[Mesh] OR "family planning program"[tiab] OR "family planning programme"[tiab] OR "family planning programs"[tiab] OR "family planning programmes"[tiab] OR "Contraceptives, Oral "[Mesh]

Medical/surgical abortion

"Abortion, Induced"[Mesh] OR "Abortion, Incomplete"[Mesh] OR "Abortion, Spontaneous"[Mesh] OR "abortion"[tiab] OR "miscarriage"[tiab] OR "pregnancy termination"[tiab] OR "termination of pregnancy"[tiab] OR "abortal"[tiab] OR "postabortion"[tiab] OR "post-abortal"[tiab] OR "postabortion care"[tiab] OR "incomplete abortion"[tiab] OR "incomplete abortions"[tiab] OR "Mifepristone"[Mesh] OR "Misoprostol"[Mesh] OR "RU486"[tiab] OR "mifegyne"[tiab] OR "Cytotec"[tiab] OR "Medabon"[tiab] OR "medication abortion"[tiab] OR "medical abortion"[tiab] OR "unsafe abortion"[tiab] OR "unsafe abortions"[tiab] OR "Extraction, Obstetrical"[Mesh] OR "Dilatation and Curettage"[Mesh] OR "Vacuum Curettage"[Mesh] OR "surgical abortion" [tiab] OR "dilation and evacuation"[tiab] OR "D&E"[tiab] OR "suction curettage"[tiab] OR "vacuum aspiration"[tiab] OR "D&C"[tiab] OR "menstrual regulation"[tiab]

Abortion-related complications

"Hemorrhage"[Mesh] OR "Postoperative Hemorrhage"[Mesh] OR "Uterine Hemorrhage"[Mesh] OR "Postpartum Hemorrhage"[Mesh] OR "Infection"[Mesh] OR "Pelvic Infection"[Mesh] OR "Uterine Perforation"[Mesh] OR "Uterine Rupture"[Mesh] OR "Pregnancy Complications"[Mesh] OR "Postoperative Complications"[Mesh] OR "Intraoperative Complications"[Mesh] OR "Emergency Treatment"[Mesh] OR "Abortion, Septic"[Mesh] OR "haemorrhage" [tiab] OR "haemorrhage"[tiab] OR "hemorrhage"[tiab] OR "bleeding"[tiab] OR "endometritis"[tiab] OR "parametritis"[tiab] OR "metritis" [tiab] OR "pelvic infection" [tiab] OR "uterine infection" [tiab] OR "uterine perforation" [tiab] OR "abortion-related complications"[tiab] OR "emergency care" [tiab] OR "ongoing pregnancy" [tiab] OR "ectopic pregnancy"[tiab] OR "emergency treatment" [tiab] OR "EmOC"[tiab] OR "emergency obstetric care"[tiab] OR "complications"[tiab] or "stillbirth"[tiab] OR "stillbirths" [tiab] OR "birth"[tiab]

HIV/AIDS

HIV[Mesh] OR HIV[tiab] OR AIDS[tiab] OR "HIV/AIDS"[tiab] OR "Human Immune Deficiency Virus"[tiab] OR "Acquired Immunodeficiency Syndrome"[Mesh] OR "Acquired Immune Deficiency Syndrome"[tiab] OR HIV-1[Mesh] OR HIV-2[Mesh] OR "HIV infections" [Mesh] OR "acquired immunodeficiency syndrome"[Mesh] OR "HIV seropositivity"[Mesh] OR "HIV seroprevalence"[Mesh] OR "AIDS serodiagnosis"[Mesh]

STIs

"sexually transmitted infection"[tiab] OR "sexually transmitted disease"[tiab] OR "Chlamydia infections" [Mesh] OR "chlamydia"[tiab] OR "Gonorrhoea"[Mesh] OR "gonorrhoea"[tiab] OR "gonorrhoea"[tiab] OR "syphilis" [Mesh] OR "syphilis"[tiab] OR "hepatitis"[tiab] OR "chancroid"[tiab] OR "trichomoniasis"[tiab] OR "human papillomavirus"[tiab] OR "HPV"[tiab] OR "genital ulcer"[tiab] OR "genital ulcers"[tiab] OR "genital wart"[tiab] OR "herpes"[tiab] OR "bacterial vaginosis"[tiab] OR "scabies"[tiab] OR "pubic lice"[tiab] OR "crab lice"[tiab] OR "pelvic inflammatory disease"[tiab] OR "PID"[tiab] OR "mucopurulent cervicitis"[tiab] OR "MPC"[tiab] OR "molluscum contagiosum"[tiab] OR "lymphogranuloma venereum"[tiab] OR "LGV"[tiab] OR "cervicitis"[tiab] OR "UTI"[tiab] OR "urinary tract infections"[tiab] OR "partner notification"[tiab]

PMTCT

"antenatal HIV test"[tiab] OR "infant HIV test"[tiab] OR "infant HIV diagnosis"[tiab] OR "option B+ "[tiab] OR "nevirapine"[tiab] OR "mother-to-child transmission"[tiab] OR "maternal transmission"[Mesh] OR "maternal transmission"[tiab] OR "vertical transmission"[tiab] OR MTCT[tiab] OR "PMTCT"[tiab]

Pregnancy, Maternal and Newborn Health

"Pregnancy"[Mesh] OR "Pregnancy, unplanned"[Mesh] OR "Pregnancy, unwanted"[Mesh] OR "Pregnancy outcome"[Mesh] OR "pregnancy in adolescence"[Mesh] OR "Pregnant"[tiab] OR "Pregnancy"[tiab] OR "IUP" [tiab] OR "Intrauterine pregnancy"[tiab] OR "Maternal health"[Mesh] OR "Maternal health"[tiab] OR "Maternal welfare"[Mesh] OR "Maternal welfare"[tiab] OR "Safe motherhood"[tiab] OR "Antenatal"[tiab] OR "Ante-natal" [tiab] OR "Perinatal"[tiab] OR "Perinatal care"[Mesh] OR "Perinatal care"[tiab] OR "Perinatal health"[tiab] OR "Prenatal"[tiab] OR "Prenatal care"[Mesh] OR "Prenatal diagnosis"[Mesh] OR "Postnatal care"[Mesh] OR "postnatal care"[tiab] OR "postnatal"[tiab] OR "post-natal"[tiab] OR "Parturition"[Mesh] OR "Postpartum period"[Mesh] OR "Postpartum"[tiab] OR "Post-partum"[tiab] OR "Puerperium"[tiab] OR "Gestation"[tiab] OR "Postbirth"[tiab] OR "Post-birth"[tiab] OR "Mother"[tiab] OR "Maternal"[tiab] OR "childbirth"[tiab] OR "obstetric"[tiab] OR "obstetrics"[Mesh] OR "gynecology"[Mesh] OR "labor and delivery"[tiab] OR "Labor pain" [Mesh] OR "Obstetric Surgical Procedures"[Mesh] OR "Delivery, Obstetric"[Mesh] OR "Safe delivery"[tiab] OR "Skilled birth attendant"[tiab] OR "Maternal Health Services"[Mesh] OR "Emergency Obstetric Care"[tiab] OR "Emergency Obstetric and Newborn Care"[tiab] OR "EmOC"[tiab] OR "EmONC"[tiab] OR "Infant"[Mesh] OR "Neonatal health"[tiab] OR "Infant health"[Mesh] OR "newborn health"[tiab] OR "Newborn infant health"[tiab] OR "Infant welfare"[Mesh] OR "Baby health"[tiab] OR "Infant, Newborn"[Mesh] OR "Fetus"[mesh] OR "Fetal therapies"[mesh] OR "Fetal monitoring"[mesh] OR "Infant"[tiab] OR "Neonate"[tiab] OR "Neonatal health" [tiab] OR "Infant health"[tiab] OR "newborn health"[tiab] OR "Newborn infant health"[tiab] OR "Infant welfare" [tiab] OR "Newborn"[tiab] OR "Stillbirth"[Mesh] OR "Stillbirth"[tiab] OR "Still-birth"[tiab] OR "women's health" [tiab]

Vaginal Injury, fistulas, cancer, infertility

"fistula"[Mesh] OR "fistula"[tiab] OR "rectovaginal fistula"[tiab] OR "rectovaginal fistula"[Mesh] OR "vaginal fistula"[Mesh] OR "urethra fistula"[tiab] OR "urinary tract fistula"[tiab] OR "genital trauma"[tiab] OR "genital injury"[tiab] OR "vaginal trauma"[tiab] OR "vaginal injury"[tiab] OR "vaginal discharge"[tiab] OR "urethral discharge"[tiab] OR "gynecologic fistula"[tiab] OR "reproductive cancer"[tiab] OR "cervical cancer"[tiab] OR "uterine cancer"[tiab] OR "ovarian cancer"[tiab] OR "vaginal cancer"[tiab] OR "testicular cancer"[tiab] OR "prostate cancer"[tiab] OR "pap smear"[tiab] OR

Gender-based violence

"gender-based violence"[tiab] OR "gender based violence"[tiab] OR "partner violence"[tiab] OR "family violence"[tiab] OR "violence against women"[tiab] OR "domestic abuse"[tiab] OR "sexual abuse"[tiab] OR "sex crime"[tiab] OR "sexual crime"[tiab] OR "domestic violence"[tiab] OR "domestic violence"[Mesh] OR "family violence"[tiab] OR "sexual violence"[tiab] OR "physical violence"[tiab] OR "rape"[Mesh] OR "rape"[tiab] OR "intimate partner violence"[tiab] OR "intimate partner violence"[Mesh] OR "partner violence"[tiab] OR "partner abuse"[tiab] OR "spousal abuse"[tiab] OR "spouse abuse"[Mesh] OR "wife abuse"[tiab] OR "assault"[tiab] OR "physical assault"[tiab] OR "sexual assault"[tiab] OR "sexual harassment"[Mesh] OR "sexual harassment"[tiab] OR "sexual coercion"[tiab] OR "forced sex"[tiab] OR "sexual slavery"[tiab] OR "abused woman"[tiab] OR "abused women"[tiab] OR "battered woman"[tiab] OR "battered women"[tiab] OR "battered women"[Mesh]

AND

Concept 3: Qualitative

((("semi-structured"[TIAB] OR semistructured[TIAB] OR unstructured[TIAB] OR "in-depth"[TIAB] OR indepth[TIAB] OR "face-to-face"[TIAB] OR structured[TIAB] OR guide[TIAB] OR guides[TIAB]) AND (interview[TIAB] OR interviews[TIAB] OR interviewing[TIAB] OR interviewed[TIAB] OR discussion[TIAB] OR discussions[TIAB] OR "focus group"[TIAB] OR "focus groups"[TIAB] OR qualitative[TIAB] OR ethnograph*[TIAB] OR fieldwork[TIAB] OR "field work"[TIAB] OR "key informant"[TIAB])) OR "interviews as topic"[Mesh] OR "focus groups"[Mesh] OR narration[Mesh] OR "qualitative research"[Mesh] OR "personal narratives as topic"[Mesh] OR "ethnography"[tiab] OR "ethnographical"[tiab] OR "ethnograph"[tiab] OR "grounded theory"[tiab] OR "phenomenology"[tiab] OR "case study"[tiab] OR "case studies"[tiab] OR "narrative research"[tiab])

Appendix 2. Key findings for each study

SRH services	Citation ID	Key findings
Abortion	Ambuel, 1992	Adolescents aged 16–17 years and adolescents ≤ 15 years, who considered abortion, appeared as competent as legal adults; Participants ≤ 15 years old who did not consider abortion appeared less competent. Competence based on 4 cognitive and volitional criteria of legal competence
Abortion	Brown, 2013	<ol style="list-style-type: none"> 1. Majority declined counselling with health professional because they were already certain about their decision 2. It was important for decisions pertaining to abortion to be discussed with known and trusted people rather than a counsellor that they feel is unknown 3. Participants had clear reasons for their decision such as not being in a position to have a baby, cannot afford child, young partner, ended relationship
Abortion	Clyde, 2013	While providers were generally positive about adolescents' ability to decide on abortion, they had different understandings about the need for adult accompaniment and who that adult should be, and mystery clients seeking information were more likely to receive complete information if accompanied by an adult. Clarification of consent and accompaniment requirements is needed, and providers need to be made aware of them; adolescents should have access to information and counselling without accompaniment; and improvements in privacy and confidentiality in public sector clinics are also needed
Abortion	Higgs, 1983	The issues of informed consent and decision making in the care of mentally handicapped patients are explored in a British case study involving a retarded, pregnant seventeen-year-old. Physicians and other health workers at the local clinic believe an abortion would be in her best interest, but the girl is unable or unwilling to make a decision or give consent, and the older couple with whom she lives is actively opposed to this solution.
Abortion	Rhenstrom Loi, 2018	The principal decision maker was often the male partner who pressed for the termination of the pregnancy indirectly by declining his financial or social responsibilities or directly by demanding termination. In some cases, the male partner controlled decision-making by arranging an unsafe abortion without the woman's consent.
Abortion	Tatum, 2012	<p>Informed consent related findings (results also report factors influencing decision-making like network support - friends. Partners, parents, sexual and reproductive health decision-making, knowledge levels and information sources as primary outcomes):</p> <ol style="list-style-type: none"> 1. Of those adolescents who terminated pregnancies, most did not appear to receive counseling from a physician or other health-care provider prior to the procedure. 2. Whereas a few of the respondents who received care in clinics were able to select the abortion method used (misoprostol or surgical), most who went to clinics did not participate in this decision, nor was the procedure explained in depth. 3. Of the nine IDI respondents who sought clinical services either for an abortion or prenatal care, health professionals respected the wishes of three who requested to be seen without parental accompaniment. However, one respondent was told she could not make any decisions herself because of her age and one girl met a physician in the public-sector services by herself who expressed judgement specifically related to her age.

Abortion (HIV)	Chibango, 2018	<p>1. Overall, both men and women expressed strong, negative attitudes towards abortion.</p> <p>2. Many participants seemed to be very religious and expressed negative views about the morality of abortion. Most appeared to be aware of abortion legislation and knew that abortion was not legal in Zimbabwe and that many abortions were carried out in unsafe conditions. They were also acutely aware of the risks associated with an unsafe abortion. Also, HIV- infected women considered carrying their pregnancy to term so as to fulfil societal and cultural expectations of childbirth after marriage/ high value of children</p> <p>3. Even though men expressed their position in terms of having control over abortion decisions, male involvement in decision making about abortion was relatively limited; if women opted for termination of pregnancy they were likely to do so secretly without obtaining their partner's consent (to avoid confrontation). Pregnancy seen as women's affair.</p> <p>4. Most female FGD participants indicated that, in the context of HIV, a woman is most likely to abort for fear of having a child that is infected.</p>
Abortion (selective terminations)	Legendre, 2009	<p>1. Information transfer Clinicians believed that it is necessary to prolong individual consultations to convey sufficiently full information and foster informed decision making. There was a lack of uniformity in the nature of the information transferred, mostly relating to information about living with a gravely ill or handicapped child, importance assigned to certain kinds of supplementary information, the forms of information preferred, and the fullness of the information disclosed.</p> <p>2. Respect for couples' autonomy All physicians considered themselves to be very respectful of couples' autonomy, but some may find it hard to implement this in practice, and felt the need to guide the couples in their decision.</p> <p>Similarities: *Necessity to devote a lot of time to information. *Importance to give the couples the maximum of time for reflection. *Belief that the final decision belongs to couples. Discordances: *Heterogeneity of revealed information. *Discrepancy in the will to assure a complete and non directive information transfer. *Divergence in representations of what is an ethical support. *Differences in the limits of the autonomy of couples.</p>
Abortion/ family planning	Princewill, 2017	<p>We found that although formal education enhanced women's ability to exercise reproductive autonomy, the culture of demanding absolute respect for men remains a major barrier. Formal education provides women with the knowledge that they need in order to access adequate health services for themselves and their children. Participants also believed that educating men was critical for the exercise of women's reproductive autonomy</p>
Abortion/ family planning	Rashid, 2011	<p>Structural inequalities and political economic, social and cultural conditions shape how rights are understood, negotiated and lived. Married adolescent women and their families remain extremely vulnerable in the unpredictable, crime-prone and insecure urban slum landscape because of their age, gender and poverty. Adolescent women's understanding of their rights such as the decision to marry early, have children, terminate pregnancies and engage in risky sexual behaviour, are different from the widely accepted discourse on rights globally, which assumes a particular kind of individual thinking and discourse on rights and a certain autonomy women have over their bodies and their lives. This does not necessarily exist in urban slum populations.</p>

Antenatal screening	Ahmed, 2013	To facilitate informed choice, midwives highlighted both the importance and challenges of engaging in discussion with women, remaining non-directive, within tight timeframes, sometimes with women unable to communicate in English or with complex social needs. Midwives varied in the degree to which they believed it was their role to (1) discuss rather than just provide information and (2) to check women's understanding of the information provided. Midwives were concerned about the constraints imposed by first trimester combined screening in terms of the limited time in which they had to facilitate informed choice and the women had to make a decision about screening. To ensure that women understand the options available to them and are able to exercise an informed choice, clinical guidelines are needed that set out how midwives can actively facilitate informed screening choices without compromising patient autonomy. This is especially important given the small 'window of opportunity' within which combined first trimester screening is a viable option.
Antenatal screening	Ahmed, 2014	Four major themes: Meanings of advice in antenatal screening/the advice continuum, Recognition of the role of health professionals in decision making, Understandings of advice in the context of autonomous decision making, and Reasons given for wanting advice. Women said they valued advice from health professionals to make decisions about antenatal screening, but their understandings of 'advice' ranged from information giving only to direction about screening choices. Many women wanted health professionals to support the process of making informed choices by engaging in discussion and did not see advice as incompatible with making autonomous choices. However, some women wanted direction about whether to have a screening test or not, something which policy and guidelines explicitly prohibit. This may cause an ethical dilemma for health professionals who are required to both support women's preference for care and adhere to a policy of non-directiveness. Further clarification is needed on how health professionals should support the process of making informed choices when women ask for clear direction on screening choices.
Antenatal screening	Al-Jader, 2000	The majority of women were not aware that screening tests were voluntary: tests were presented as routine. About half of the sample were not well informed to make decisions. Only five out of a sampling frame of 101 women refused screening; they tended to be better educated and of higher social class. All women wanted to be given the choice whether to be screened.H46
Antenatal screening	Barr, 2013	information overload, gaps in information, challenges in providing information and involvement of both parents in the decision. Parents and professionals believed that burdening parents with untimely information on a wide range of topics in the first trimester detracted from decision making about screening. Many parents also reported they were not sufficiently informed and wanted individualized discussion with a health professional.
Antenatal screening	de Jong, 2013	Two major themes emerged in the focus groups. Participants first focused on features of the test options, such as test outcomes, wait for results and costs and classified these as pros and cons. Secondly, a more reflective discussion started about the meaning of informed choice and autonomy in the prenatal screening context. Participants wanted to be enabled to make informed choice about what test to apply, but disagreed about the feasibility of this ideal
Antenatal screening	Farsides, 2004	Practitioners managed the interface between their professional and private moral values in a variety of ways. Two key categories emerged: "tolerators", and "facilitators". The majority of practitioners fell into the "facilitator" category. Many "facilitators" felt comfortable with the prevailing ethos within their unit/institution, and appeared unlikely to feel challenged unless the ethos was radically challenged - women's right to choose is paramount. For others, the separation of personal and professional moral values was a daily struggle. In the "tolerator" group, some practitioners sought to influence the service offered directly, whereas others placed limits on how they themselves would contribute to practices they considered immoral - greater virtue in allowing others to exercise their autonomous choices.
Antenatal screening	Hunt, 2005	Clinicians and patients have different goals, purposes, and values regarding testing, which affect their clinical interactions. The information the clinicians provide patients reflects their clinical interest in identifying and controlling pathophysiology, while patients, in contrast, are most concerned with protecting and nurturing their pregnancy. Parents sometimes conclude that testing is the only practical option. We argue informed patient decision-making about prenatal testing options requires information that is responsive to patient interests.

Antenatal screening	Levy, 1999	<p>Core category: maintaining equilibrium When maintaining equilibrium, a woman sought and dealt with information in such a way as to protect and keep in balance the interests of herself, her baby, partner and others, during a period often involving considerable change. The part played by midwives in providing and helping women use this information was crucial: women appreciated midwives who appeared trustworthy, supportive and genuinely concerned to help them make real choices.</p> <p>Substantive categories:</p> <ol style="list-style-type: none"> 1. Regulating information by 1) avoiding receiving information if they regarded it as irrelevant to their situation 2) delaying pursuing information they required because they felt the time was not right for that topic to be addressed and there were other topics of more immediate concern 3) In more difficult areas such as difficult choices or distressing situations, women often felt some degree of ambivalence although on the whole, they want more information 2. Contextualizing information - referring to how women legitimated information (assessed its validity, together with the trustworthiness of the person providing it), and personalized the information in terms of its value and applicability to themselves as individuals possessing unique circumstances, attitudes and priorities. 3. Actioning - Women did not always find it easy to state or achieve their wishes; power-related issues affected the strategies women employed when stating and implementing their choices. The strategies that they employed to address this include asserting, playing the game, taking it as it comes, and handing over.
Antenatal screening	Ockleford, 2003	<p>This qualitative study found an alarming level of misunderstanding surrounding the purpose of ultrasound scans and serum testing. Findings show that some women did not understand that they were free to choose whether or not to have tests. Some who did understand the optional nature of the tests were making decisions based on poor understanding of what the tests were for or of the nature of the results they would yield. Some are not prepared to take responsibility for their choice concerning tests, preferring to leave these responsibilities to others such as doctors</p>
Antenatal screening	Oliver, 1996	<p>With the aim of promoting the informed choice of pregnant women, staff and pregnant women at two urban hospitals were offered leaflets summarizing the best available evidence about the effectiveness of routine ultrasonography in early pregnancy. Ultrasonographers doubted the credibility of the evidence and were concerned that the leaflets would raise women's anxiety, reduce uptake of scans, disrupt hospital organization, and reinforce media messages about the poor safety record of ultrasonography. Midwives thought that the leaflets would inform women, help them to talk about their care with health professionals, and help them to get better care. Women were shocked at some of the contents but thought that it was appropriate to include both advantages and disadvantages of routine scanning in the leaflet. This case study highlights the resistance of some health professionals to evidence-based health care; underlying conflicts with the principle of professional autonomy; concern that informed choice may create anxiety; and professional and organizational barriers to allowing informed choice.</p>
Antenatal screening	Pilnick, 2016	<p>Whilst previously identified formats are used here to present the need for a decision, the overriding basis professionals suggest for actually making a decision in this context is the level of worry or concern a pregnant woman holds about potential fetal abnormality. Professionals take an unknowing 'epistemic stance' (Heritage) towards this worry, and hence step back from involvement in decision-making. We argue that this is linked to the non-directive ethos that prevails in antenatal screening service</p>
Antenatal screening	Potter, 2008	<p>Many, but not all, participants seemed to have made informed decisions about prenatal testing: aware they had a choice, demonstrated sufficient knowledge (personal implications of testing and relevant technical information were considered) and made a decision that was consistent with their values. Values and knowledge were interrelated and important components of informed choice, but the way they were discussed differed from the way they have been presented in scientific literature. In particular, 'values' related to expressions of women's moral views or ideas about 'how life should be lived' and 'knowledge' related to the ways in which women prioritized and interpreted factual information, through their own and others' experiences and in 'thinking through' the personal implications of testing. While some women described non-directive discussions with health professionals, others perceived testing as routine or felt pressured to accept it.</p>

Antenatal screening	Tsianakas, 2002	<p>Ultrasound</p> <ol style="list-style-type: none"> 1. Provided them with a sense of assurance of the health and well-being of the unborn child 2. Some were ambivalent about testing, attributing it to anxiety of having multiple tests offered 3. Many women accepted ultrasound as part of their antenatal care and responded positively. However, Islamic beliefs always permeated through discussions. <p>Amniocentesis</p> <ol style="list-style-type: none"> 1. Most of the women perceived the amniocentesis to cause potential harm to their unborn child and they therefore responded negatively to it. The overall attitude was that the risks outweighed the benefits. <p>Overall experiences with prenatal testing / other views</p> <ol style="list-style-type: none"> 1. Women had complete trust in doctors. Whatever the doctors recommended or offered to them, they perceived as good advice to follow. 2. To the women, Islam encourages the use of prenatal testing if it does not endanger the life of the mother or the baby. Women, therefore, did not reject the idea of having prenatal testing during pregnancy. 3. According to the women, Islam prohibits abortion and abortion is only allowed in the instances where the mother's life is endangered. However, some women did allow room for termination if severe abnormalities were diagnosed, particularly those associated with the brain or heart which would mean the child would not be able to function as a human being. 4. Women perceived that husband's had positive attitudes towards prenatal testing. Husbands were also thought to be positive.
Antenatal screening	Williams, 2011	<p>Male partners of pregnant women:</p> <ol style="list-style-type: none"> 1) feel ambivalence, doubt, and uncertainty regarding medically identified risk 2) "emotional rollercoaster" 3) men and partners do mediation and shared decision-making 4) limited engagement with midwives and other health professionals
Antenatal screening	Farrell, 2014	<p>Three themes were relevant to newborn bloodspot screening (NBS) consent: (1) The 'offer' of NBS; (2) content and timing of information provision; and (3) the importance of parental experiences for consent decisions. Recollections of consent for NBS were similar between jurisdictions. Excepting midwives and their patients, NBS was viewed as a routine part of giving birth, with little evidence of an informed consent process. Although most parents were satisfied, all respondents suggested information about NBS be provided long before the birth. Accounts of parents who declined screening highlight the influence of parental experiences with the heel prick process in screening decisions.</p>
Antenatal screening (Cell-free fetal DNA)	Farrell, 2019	<p>Partners of pregnant women wished to be actively involved in testing decisions as a way to support their current/future family. They articulated a distinct set of needs and preferences in the decision-making process. Viewed that collaborative decision-making was seen as part of an obligation to the pregnant woman and family. Noted the inherent biological and medical-legal limitations to their ability to alter the course of prenatal care, but reported an interest, need and/or sense of obligation to participate in the decision-making process. Described that extent of involvement ultimately dependent on the preferences and choices of the pregnant woman. Such involvement was hindered by several biological and logistical barriers. This study demonstrates the need to develop mechanisms that foster informed decision-making for cfDNA screening and related new reproductive genetic technologies that focus on not just the pregnant woman but also the decision-making dyad that includes her partner as well</p>
Antenatal screening (Down Syndrome)	Chiang, 2006	<p>Reasons on which pregnant women appeared to base their decisions when undergoing MSS. The reasons were first, the recognition that the procedure was a prenatal routine procedure; second, the need to avoid the risk of giving birth to a baby with Down's syndrome, and third, a trust in modern technology and in the professional authorities.</p>

Antenatal screening (Down Syndrome)	Lewis, 2013	<p>The overwhelming majority of women viewed NIPT as a positive advancement in prenatal care, highlighting numerous practical and psychological advantages of a safe test that was highly accurate and could be conducted early in pregnancy. Concerns raised were that testing could become routinised, and that pressure to test might occur with women feeling less justified in declining a blood test that is available and offered by trusted health professionals; the impact on the disabled community and stigma for women who decline testing was also noted. Nevertheless, the vast majority of women said they would be likely to use NIPT, including half of the women who currently decline screening. Women's preference was for pre- and post-test counselling to be delivered by a midwife.</p>
Antenatal screening (Down Syndrome)	Santalahti, 1998	<ol style="list-style-type: none"> 1. Although screening was presented as voluntary, half of the women said that they considered participation to be routine, a self-evident act or "natural". This was due to factors such as strong trust in the maternal care system, and not recognizing that the nature of this test was different from other tests in maternity care. 2. Factors that weakened women's prerequisites for informed consent or the lack of participation in decision-making include hurry and anxiety; time, anxiety, trust in healthcare provider, first-time pregnancy. 3. About half of the women (22 of 43) mentioned their partner in connection with decision-making in diagnostic tests. Men's roles varied greatly: from mutual decision-making or participation being a self-evident act for both. 4. In relation to screening practices, the kind of information most often desired was that about the conditions the screenings can reveal and secondly about technical characteristics of the tests, e.g. false positive and false negative results, and about diagnostic tests. Several women wished that women would be supported in thinking more profoundly about the matter and not just given information and left alone.
Antenatal screening (Down Syndrome)	Tsouroufli, 2011	<ol style="list-style-type: none"> 1. Although the possibility of having a child with Down's syndrome was always mentioned in community bookings, midwives approached first trimester screening with optimism. They emphasized the small likelihood of having an abnormal fetus, and reinforced the positive experience of being pregnant and delineated the medical surveillance including the screening that was available. 2. The possibility of opting out of first trimester screening at any stage was always raised, and midwives reinforced antenatal screening for Down's syndrome as a personal choice. 3. Pre-screening consultations with health care assistants and midwives indicated that there is a general expectation that women would take up first trimester screening. Leading information, inadequate purposeful dialogue 4. The short pre-screening information offered at the clinic in a context of routinization, followed by routine blood tests and ultrasound scan, may have encouraged uptake of testing due to the opt-out system.
Antenatal screening (Down syndrome)	Watterbjork, 2015	<p>Three different patterns were identified relating to couples' decision-making processes about participating or not in the combined test:</p> <ol style="list-style-type: none"> a. The open and communicative decision-making process: Most of the couples in this pattern had made a reflected decision to accept or decline the combined test. They had formulated their own reasons for participating or not. Most of the couples had had an on-going discussion with each other until they reached a joint decision. b. the closed and personal decision-making process: Most of them focused on only one argument for participating and made their decision at or right after the information session. Their argument was more about having the opportunity to participate in the screening rather than an expressed willingness to participate. c. The searching and communicative decision-making process: all in their thirties and expecting first child. These couples discussed the matter in depth with each other and tried to communicate and discuss with others the decision about participating in the test. They discussed the issue with family and friends, and sometimes, they encountered different opinions. This gave them new perspectives and new ideas for how to think about the decision, and it helped them to reach a decision.

Antenatal screening (Down Syndrome)	Williams, 2005	<ol style="list-style-type: none"> 1. Men's views and experiences of antenatal genetic screening and testing were often characterized by ambivalence, doubt and uncertainty, not least in their relationship to their perceived worth to the health of their partners and babies. Some thought that the requirement for screening and testing was assumed by health professionals, hence limiting men's and their partner's decision making. 2. There were anxieties and uncertainties associated with screening and testing, which created emotional tensions for men. 3. The involvement of men in decision making was influenced by the fact that they did not feel as emotionally connected as their partners to the medical processes as they believed they did not have the same physical embodiment of pregnancy as women. 4. Men expressed that a greater engagement with midwives and other professionals will alleviate their anxieties and allow them to have greater involvement in the pregnancy.
Antenatal screening (Down Syndrome, sickle cell, thalassaemia)	Ahmed, 2012	Choice as individual right "my body, my baby, my decision" (personal autonomy - mother's right to make decision, angry if tested without permission), strongly agreed with making testing decision with partner but disagreed with partner making testing decision for them (decision is mother's even if it goes against partner's wishes), health professionals seen as information providers/advice givers (disagreed with leaving testing decision to health professionals because it's a personal decision)
Antenatal screening (fetal aneuploidy)	van Bruggen, 2018	<ol style="list-style-type: none"> 1. There were no major differences in decision-making between the two time periods. Most women stated that they had made a 'deliberate' decision, weighing all the pros and cons. However, there were individual differences in the time and resources women used to make the decision. 2. Most women framed their decisions in the context of their perceptions of Down syndrome and their attitudes towards termination of pregnancy. During the decision-making process, women considered whether they were able or willing to offer the extra care needed when having a child with Down syndrome, and what impact it would have on them- selves and their families. 3. Women considered whether they would opt for termination of pregnancy should they be pregnant with a child with Down syndrome. This was influenced by factors such as religion and beliefs on nature and fate. 4. Some declined screening due to the uncertainties and anxiety on several factors, such as the risk of a child with Down syndrome, the probabilistic test outcome, and the process of waiting for the results. 5. Several women included experiences from their own social environment in the decision-making process. These included experiences such as as miscarriage, difficulty getting pregnant and already being a mother. 6. Between the two time periods, there were some differences. These were due to 1) availability of non invasive prenatal testing and a 20-week ultrasound scan 2) differences in cost 3) greater media influence on decision-making
Antenatal screening (fetal testing)	Maridosian, 1990	Prenatal screening acceptance and refusal should not be viewed as contrasting decisions, women who make these apparently opposite 'choices' hold significantly disparate views towards biomedicine and abortion. The women's accounts of their prenatal screening decisions reveal that although their 'choice' about screening is binary, their explanations are more accurately viewed as falling along a continuum between full acceptance and complete rejection of medical authority over their pregnancies. Viewing women's accounts about prenatal screening in this way highlights the fact that medicalization processes are not absolute, nor are pregnant women's decisions in the face of these processes all or nothing reactions to modern, rationalized and medical control of their reproductive experiences.
Antenatal screening (first trimester aneuploidy/ Down Syndrome)	Farrell, 2011	Multiple levels of uncertainty characterize the decision-making process for first trimester aneuploidy screening. Baseline levels of uncertainty existed for participants in the context of an early pregnancy and the debate about the benefit of fetal genetic testing in general. Additional sources of uncertainty during the decision-making process were generated from weighing the advantages and disadvantages of initiating screening in the first trimester as opposed to waiting until the second. Questions of the quality and quantity of information and the perceived benefit of earlier access to fetal information were leading themes. Barriers to access prenatal care in early pregnancy presented participants with additional concerns about the ability to make informed decisions about prenatal genetic testing.

<p>Antenatal screening (maternal alpha-fetoprotein screening)</p>	<p>Markens, 1999</p>	<ol style="list-style-type: none"> 1. The routinization of prenatal screening - vast majority of women who were offered prenatal screening accepted it because it was presented as the medically and maternally responsible course of action 2. Those who refused saw prenatal screening as connected with abortion despite the fact that the link was assiduously played down in the health maintenance organization (HMO). 3. Decision was not necessarily the result of strong opposition to the test itself but rather depended on context and practical considerations. 4. Refusers and acceptors evaluated differently the information prenatal screening could provide. For instance, while acceptors said that the information provided by the test would ease their mind', most of the refusers expressed concern about the problems such information could bring, particularly if something wrong was discovered. 5. Perception that screening was not essential. 6. Different conceptions of risks - for acceptors it was the absence of such information that seemed 'risky', whereas refusers declined the test because the information it provided posed various 'risks'.
<p>Antenatal screening (Non-invasive prenatal genetic diagnostic (NIPD))</p>	<p>Kelly, 2012</p>	<ol style="list-style-type: none"> 1. NIPD does not raise new social and ethical questions, but extends or exacerbates concerns with current practice. These suggest that unease exists in some public attitudes concerning the public health rationale and societal implications of prenatal screening programs, and of their expansion. 2. Concerned about the implications of commercial availability of NIPD testing, such as being offered in a commercial setting without 'appropriate advice and guidance', as well as a lack of monitoring, medical oversight and support. 3. A majority was showed ambivalence. While many saw benefits for pregnant women and families, there was expression of fear that NIPD will exacerbate societal attitudes perceived to be associated with current prenatal screening, particularly promoting attitudes toward 'perfection' in reproduction. A number of respondents also expressed that decisions associated with current prenatal testing programs are difficult and perhaps currently not adequately supported. 4. NIPD raises questions about limits on the use of prenatal genetic diagnosis. Participants are particularly concerned about possible availability of testing outside of the health service context and because testing would be 'easier'.
<p>Antenatal screening (noninvasive prenatal testing)</p>	<p>Farrell, 2014</p>	<ol style="list-style-type: none"> 1. Women identified accuracy, early timing, testing ease, and determination of fetal sex as advantages of NIPT over other screens, and the noninvasive method of NIPT as an advantage over diagnostic tests. 2. False positive and false negative results, anxiety, cost and insurance coverage were seen as disadvantages of NIPT. 3. Women who do not want fetal aneuploidy information most likely will not undergo NIPT, despite its advantages over other screening tests. 4. However, given its advantages, the decision to have NIPT is straightforward for women who want genetic information about the fetus. 5. Women emphasized the need to make autonomous, private, and informed choices about NIPT, as they would with any prenatal genetic testing option. Pregnant woman should make final decision for prenatal genetic testing, and control information disclosure/privacy.
<p>Antenatal screening (sickle cell and thalassaemia) in primary care</p>	<p>Tsianakas, 2012</p>	<ol style="list-style-type: none"> 1. The perception of the benefits of early screening. All women felt it should be offered as early as possible believing early diagnosis would provide them with more options when making decisions about their pregnancies. 2. Satisfaction and expectations of participation and involvement in decision making when offering screening. Many women felt satisfied with the offering screening and had low expectations of choices. Most of them were given time to think about the decision. Doctors were believed to be acting out of concern for the women's well-being. 3. The need for information. Despite their low expectations of choice, many women felt general practitioners did not spend enough time explaining the conditions for which screening was being offered. Consequently, they felt ill informed.

Antenatal screening (thalassaemia carrier testing)	Ahmed, 2005	Women had received little or no pre-test information and said that they would have preferred to be informed that they were being tested, but they did not expect, or express a desire, to be asked for their informed consent. While information was important to women, consenting was not. Overall, women discussed 'information' and 'consent' as two separate issues, thus challenging assumptions around the term informed consent. Women wanted pre-test information because they wanted to know more about the tests that they would be having, not to use it to make decisions about whether to have the tests.
Antenatal screening (ultrasound)	Firth, 2011	The majority of women desired ultrasonography despite many not understanding the procedure or purpose. Patient's expectations included discovering fetal position, fetal sex and pregnancy problems. However, women frequently over-estimated the capacity of ultrasound, and had significant fears of harm. One sixth of questionnaire respondents said they did not want ultrasonography. Nonetheless since the service was introduced no woman has declined, and numerous interviewees believed scans were obligatory. Despite fears, some women reported enjoyment of ultrasound. Interviewees believed ultrasound would increase antenatal care (ANC) attendance. An informed consent policy and an education campaign are needed to reduce fears and maximize uptake and health gains.
Antenatal screening (β -thalassaemia)	Cousens, 2013	Most women did not recall being told about thalassaemia before notification of their carrier status and therefore did not make a decision about being screened. They were generally accepting for doctors to decide about testing; however, would have preferred to have been made aware of the screening test. Women also reported receiving insufficient information after being notified of their carrier status, leading to misconceptions and confusion. This genetic screening process, incorporated into routine care whereby informed decisions were not being made by patients, was apparently acceptable overall
Antenatal screening (β -thalassaemia carrier)	Cousens, 2014	Participants described and acknowledged inconsistencies in the β -thalassaemia screening processes, such as variability in ordering the tests, communicating the diagnosis, and action taken after diagnosis. They indicated a preference for more structure and valued the importance of screening guidelines but many of those involved in ordering the screening test were unaware of their availability. These healthcare professionals recognized they lacked knowledge regarding the screening process, and many had not undertaken education activities in this area in recent times. There were mixed views about the consent process, particularly at which stage this should be obtained, and what information is provided. Different views regarding informed consent, e.g. implied consent (by patients agreeing to provide the blood sample) is sufficient vs. that verbal consent is necessary vs. that 'informed consent' should be provided, which in this context appeared to equate to 'provision of information'.
Circumcision (neonatal)	Fay, 2016	Prior to using the intervention, clinicians used a consent document to frame circumcision as a default practice. Encounters with the Option Grid conferred agency to both parents and clinicians, and facilitated shared decision-making - provided parents an opportunity to ask questions, raise concerns, become more engaged with decision-making process; enabled providers to collaborate, clarify preferences, and provide information. Clinician reported recognizing the tool's positive effect on their communication process.
Circumcision (VMMC)	Friedland, 2013	Results indicated confusion between "risk" of adverse surgical outcomes and reduced "risk" of HIV; most respondents acknowledged the 6 week abstinence period post-VMMC, yet few said resuming sex early increases HIV risk.
Circumcision (VMMC)	Schenk, 2012	Data reveal complex interactions between adolescent and parent/guardian regarding making and authorizing the decision to circumcise. High perceived but poor actual comprehension of MC (issues with counseling). Informed consent procedures for minors are poorly understood and inconsistently implemented at clinic sites, at a time when regulation was changing.

Circumcision (VMMC)	Schenk, 2014	Some clients equated written informed consent with releasing the clinic from liability. Most clients felt well prepared for the procedure, although many were surprised by the level of pain experienced during anesthesia and postsurgery. Clients were highly motivated to adhere to wound care, but some were overwhelmed by extensive instructions. Adolescents described barriers to accessing follow-up care and the need for support in overcoming adult gatekeepers. Key opinion leaders indicated that informed consent is not well understood in poorly educated communities.
Contraceptive services	Calhoun, 2013	Providers, at times, make judgments about their clients' education, FP needs and ability to understand FP options thereby imposing unnecessary barriers to FP methods. Doctors reported restricting clients' access to long acting and permanent methods such as sterilization (91%) and IUCD (70%) based on the need for partner consent more frequently than they restricted short term methods, such as condoms (13%) or pills (21%). Nurses also reported restricting clients' access to pills (50%), condoms (30%) and IUCD (85%) based on partners' consent. Approximately one quarter of midwives restricted client access to pills and condoms based on partner consent and nearly 75% restricted access to the IUCD based on partner consent. Approximately half of TBAs restricted access to pills and IUCD based on partner consent, while only 13% restricted access to condoms based on partner consent. Providers may perceive that women have little power to independently make choices about FP use or their own fertility; therefore providers may decide what methods to offer based on factors such as age, marital status, parity, and education. These providers may combine this information with existing cultural norms as guidance for FP method provision, even if not medically appropriate.
Contraceptive services	Dehlendorf, 2014	Providers employed three counseling approaches: foreclosed (in 48% of visits), characterized by discussion of few contraceptive methods and method selection by the patient with no involvement from the provider; informed choice (30%), characterized by detailed description of multiple methods, but little or no interaction between the patient and the provider; and shared decision making (22%), characterized by the provider's interactive and responsive participation with the patient in method selection. Use of these approaches varied by patient's age: Women 25 or younger experienced the foreclosed approach more often than older women, and patients older than 35 were far more likely than their younger counterparts to experience the shared decision-making approach.
Contraceptive services	McCarthy, 2010	Most of the women reported that it was other people who made the key decisions about starting to use contraception and which method to use. Both the women and the doctors said they liked having a third party (staff member or relative) present for the consultations. Many of the doctors were unclear about responding to issues of capacity to consent to treatment.
Contraceptive services	Stanback, 2001	Providers enforced a variety of restrictions known to impede clients' access to services. Concerns about client safety and morals were the most often cited rationales for restricting services according to age and parity. Many providers were especially concerned that contraceptives might cause future fertility problems, and used minimum age or parity requirements to ensure that only women of proven fertility could obtain contraceptives. A number of providers apparently believed in particular that injectable contraceptives cause permanent infertility. Providers also cited health concerns as the reason for enforcing strict resupply and revisit schedules, as well as for routinely conducting laboratory tests.

Contraceptive services	Sundstrom, 2018	Participants expressed a preference for relationship-centered care, in which healthcare providers listened, individualized their approach to care through rapport-building, and engaged women in shared decision-making about contraceptive use through open communication, reciprocity, and mutual influence. Conflicting health messages served as barriers to uptake of effective contraception. While participants trusted their healthcare provider's advice, many women prioritized personal experience and autonomy in decisions about contraception. Providers can promote trust and relationship-centered care to optimize contraceptive uptake by listening, exploring patient beliefs and preferences about contraception and birth spacing, and tailoring their advice to individuals. Results suggest that antenatal contraceptive counseling should incorporate information about effectiveness, dispel misconceptions, and engage patients in shared decision-making.
Contraceptive services	Yee, 2011	Features of negative counseling experiences included having insufficient, non-physician-directed and impersonal counseling. Most women had experienced episodes of poor communication with providers; 10 described feeling coerced or perceiving racially-based discrimination in counseling.
Contraceptive services (emergency contraception)	Wilkinson, 2014	Four major themes emerged. First, ethical terms (personal or religious) were used to explain institutional pharmacy policies on EC availability. Second, there was confusion about the dispensing regulations regarding EC, given recent changes in United States policies. Third, pharmacy staff often introduced false barriers to EC access. In some cases, pharmacy staff used these barriers as justification for refusing to dispense EC; however, in other cases, pharmacy staff helped the adolescents overcome these false barriers. Finally, the degree of confidentiality in providing EC was unpredictable, with some pharmacies guaranteeing strict confidentiality and others explicitly telling adolescents, incorrectly, that their parents had to be informed.
Contraceptive services (immediate postpartum IUD insertion)	Carr, 2018	An unanticipated theme that emerged was an ineffective informed consent process; women could not recall most procedural risks or how IPPI was accomplished, though they overwhelmingly perceived counseling to be adequate in providing information for an informed decision
Contraceptive services (postabortion)	Brandi, 2018	<ol style="list-style-type: none"> 1. Some participants (42%) referenced some provider pressure to choose a form of birth control during post-abortion care. Others perceived that providers had an agenda to promote contraception 2. Participants endorsed repetitiveness in counseling, which was perceived as coercive, judgmental 3. Eight participants (26%) perceived pressure to use specific methods post-abortion. The majority of these women expressed feeling pressure to use an intrauterine device (IUD)/LARC. Participants managed this pressure to use a specific method in different ways. Again externalizing difficult subject matter, one explained that this type of counseling could lead other women to choose this method because they felt they had no other choice available to them 4. Some perceived that the provider's motivation to encourage contraception at the time of abortion was to prevent repeat abortion, extending previously described narratives around provider pressure and coercion around contraceptive method selection. 5. Participants who heard a range of options from providers, with relevant pros and cons presented, demonstrated language showing more control over their decisions. After comprehensive contraceptive counseling, one person said that she "felt better equipped" to make her contraceptive decision. Another participant shared that by getting all of the information she felt her provider was impartial. Providing a range of options was associated with language reflecting self-efficacy and autonomy and perceptions of unbiased care. 6. Conversely, women who were offered limited contraceptive options expressed less control over their ability to make an informed decision

Contraceptive services (postabortion)	Jerman, 2019	Many respondents noted that not all abortion patients want contraceptive care, and that they do not want to coerce or shame patients through unwanted contraceptive counseling. For these participants, it was often difficult to find ways to respect the full range of patients' preferences, such as by avoiding contraceptive counseling for those who don't want it while ensuring robust counseling and education for those who do. Some providers also expressed a goal of having every patient leave with a method, which could represent an additional conflict for providing patient-centered care. It was also difficult to find the right balance of information to provide, as some patients experience "information overload" during the course of the abortion appointment when coupled with the informed consent process.
Contraceptive services (sterilization/hysterectomy)	Chou, 2011	Decision-making regarding sterilization (tubal ligation/hysterectomy) for women with intellectual disabilities (ID) living with their families, including how such decisions are made and who is involved in the decision-making. Almost none of the women with ID were involved in the decision-making process, and some were not even informed of the nature of the surgery. Health professionals and service workers contacted by the families were also influential in the decision-making. The autonomy of the women to engage in decision-making regarding sterilization thus was constrained by their families and professionals, without considering either sterilization or hysterectomy a violation of the essential human rights of the women involved.
Contraceptive services (sterilization/hysterectomy)	Entwhistle, 2006	The interview accounts suggested that gynecologists offered women little opportunity to influence the selection of a surgical procedure. Women did not express a desire for a greater say in this selection, but appreciated being told, or would have liked to know, why particular procedures were recommended for them. There may be circumstances in which it is important for surgeons to tell patients about options they have ruled out in their particular cases. Decisions between alternative surgical procedures are often highly contingent on the dispositions and skills of individual surgeons. They raise practical and ethical issues that have been neglected in recent discussions about patient involvement in decision-making.
Contraceptive services (sterilization/hysterectomy)	Richter, 2002	<ol style="list-style-type: none"> 1. Women perceived that the main role of a physician is that of an information provider. This was also the role that physicians perceived of themselves. 2. Nature of the physician-patient communication was perceived by many women as important and as often not satisfactory, especially among African-American women. 3. Most viewed physician's role as limited to recommending the procedure and providing information. 4. Women were clear about the need for a second opinion due to wanting a peace of mind or not trusting the medical professional. 5. Most of the physicians interviewed saw themselves as those who give the facts and make a recommendation, and most concluded that their personal style of physician-patient interaction was optimal. 6. Most physicians indicate that the patient is the one who ultimately makes the decision of whether to have the hysterectomy. 7. Most of the physicians seemed willing to defer to a woman's decision not to have a hysterectomy that they recommended. They also indicated that they would not perform a hysterectomy at the woman's request if they did not think it was necessary.
Contraceptive services (sterilization/hysterectomy)	Rodriguez 2015	Coercive or forced sterilization or administration of contraceptives; abuse when visiting a gynecologist.

Contraceptive services (sterilization/hysterectomy)	Strode, 2012	Participants all reported being sterilized between 1996 and 2010 without their informed consent (n=18) or without their knowledge (n=4). Key issues reported by participants included failure to respect their autonomy, lack of information given about what sterilization entailed, and subtle or overt pressure to sign the consent form. Although the legal framework was intended to ensure informed decision-making regarding sterilization, these protections appear to have failed the HIV-positive women in this study. The findings suggest that some health professionals may consider a signature on a consent form as sufficient regardless of how it was obtained.
HIV testing	Bokhour, 2009	<ol style="list-style-type: none"> 1. Women perceived that the main role of a physician is that of an information provider. This was also the role that physicians perceived of themselves. 2. Nature of the physician-patient communication was perceived by many women as important and as often not satisfactory, especially among African-American women. 3. Most viewed physician's role as limited to recommending the procedure and providing information. 4. Women were clear about the need for a second opinion due to wanting a peace of mind or not trusting the medical professional. 5. Most of the physicians interviewed saw themselves as those who give the facts and make a recommendation, and most concluded that their personal style of physician-patient interaction was optimal. 6. Most physicians indicate that the patient is the one who ultimately makes the decision of whether to have the hysterectomy. 7. Most of the physicians seemed willing to defer to a woman's decision not to have a hysterectomy that they recommended. They also indicated that they would not perform a hysterectomy at the woman's request if they did not think it was necessary.
HIV testing	Burrage, 2008	Most viewed opt-out screening as an acceptable approach to HIV testing. Many emphasized the importance of provision of explicit verbal informed consent. The majority strongly opposed the elimination of the requirement for pretest prevention counseling and spontaneously talked about the ongoing importance of posttest counseling. There was a concern about confidentiality and that people might be coerced into being tested under the guise of opt-out testing. The notion of lack of trust of health care providers and the health care system in the context of patient rights about having a choice to have a test or not emerged in women's responses to the recommendations that there would no longer be clear and specific written informed consent prior to testing. An ethical concern emerged in the responses about the necessity of education to explain the test and procedure in enough detail so that patients would have as much information as they needed to make a truly informed decision about the choice to be tested. The conclusion was that there was strong support for universal testing of all persons 13 to 64 years old but scant support for the elimination of pretest prevention counseling. In general, respondents believed that verbal informed consent for testing as well as provision of HIV-related information before and after testing were crucial.
HIV testing	Cowan, 2013	Participants believed that opt-out consent would result in increased testing, but this was confounded by misunderstanding of the consent process: "so the opt-out is, you basically don't have a choice." Participants thought eliminating separate written consent was a positive change but that it could result in people being tested without their knowledge. Attitudes diverged over curtailed counseling, but participants felt patients "should have options" for counseling because "everybody isn't the same."
HIV testing	Groves, 2010	Half of the women described having a clear choice in their decision to test (positive interaction at ANC, autonomy in decision-making). Others were less clear about their choice (ambiguous interactions at ANC). Some women felt they had no choice in testing for HIV (compromised consent, negative interactions). None of the women stated that they were tested without having signed a consent form. We found that half of the women's narratives illustrated direct and indirect ways in which providers coerced them into taking an HIV test while receiving antenatal care.

HIV testing	Hardon, 2012	Our qualitative findings reveal that some women found testing regimes to be coercive ("it was hard not to be tested", felt like they had the right to refuse but sometimes felt pressured by doctor to test, some said testing was mandatory, opting out was described as intimidating and a burden to health workers), while disclosure remains highly problematic (fear blame, abuse, abandonment).
HIV testing	Heckert, 2001	Women wanted to know about treatment that significantly reduces the risk of mother-to-child transmission. They wanted to know about other antenatal screening and were prepared to provide general consent, rather than specific consent for HIV testing. All study participants favoured routine offer of HIV testing during pregnancy for all women and most would agree to be tested, if the test was offered and recommended.
HIV testing	Kedote, 2011	Apart from three cases of secret HIV testing, the free nature of the consent to HIV testing is respected on the PMTCT sites. Twenty-nine cases of refusal were recorded. The reasons put forth by most pregnant women include the fear of a positive test and its consequences on family life and the expectation of their husbands' agreement or disagreement. On the whole, the consent was free on all the sites but its informed nature is less respected.
HIV testing	Leidel, 2015	Eleven participants had a questioning attitude toward opt-out HIV testing, while eleven favored the approach. The remaining two participants had more nuanced perspectives that incorporated some characteristics of the questioning and favoring attitudes. Participants' views about opt-out HIV testing largely fell into two contrasting themes: normalization and routinization versus exceptionalism (of HIV testing - HIV prevention was a benefit of the opt-out method, and could decrease stigma, which would have broader societal benefits. Routinization of the test was also seen as beneficial as it reassures patients that they are not singled out.); and a need for proof versus openness to new approaches (Majority of the participants had a questioning attitude toward opt-out HIV testing cited a lack of rationale or evidence for a change in testing strategy. In their view, opt-out HIV testing would be reasonable only if there was risk factor-based evidence to support it. Need for proof was also framed in terms of cost-effectiveness, and was associated with a fear of reprimand, such as questioning by government funding bodies (Medicare). It was also seen as important in protecting HCPs delivering what they perceived to be potentially contentious care. In contrast, openness to new testing approaches was a common attitude among participants who favored opt-out HIV testing, citing the benefits of HIV testing and positive outcomes from other countries.).
HIV testing	MacCarthy, 2014	'Quality' was defined according to global and national guidelines as HIV testing with informed and voluntary consent, counselling and confidentiality (3Cs). No pregnant woman Experienced all elements of the 3Cs. Three women did not experience any informed and voluntary consent, counselling or confidentiality. Few women provided consent overall and none received pre-test counselling. Post-test counselling and confidentiality of services were more consistently provided. Lack of explanation by practitioner regarding nature of consent, highlighting that there are varying degrees of consent, concrete definitions of "informed" and "voluntary" are elusive in practice, lack of comprehensive counseling.
HIV testing	Manongi, 2014	Knowledge about PITC services was generally low. Compared to men, women had a more positive attitude towards PITC services, because of its ability to identify and treat undiagnosed HIV cases. HIV stigma was regarded as a major barrier to patients' uptake of PITC. Institutional factors such as lack of supplies and human resources were identified as barriers to successful provision of PITC.
HIV testing	Noland, 2015	All participants were receptive to opt-out HIV testing, and saw the removal of separate written consent as beneficial as long as patients were given the opportunity to consent in some form

HIV testing	Pollard, 2013	There was broad support for opt-out HIV testing based on public health and individual health benefits. For this sample, opt-out HIV testing when registering with a general practice surgery and on elective or emergency admission to a general hospital was acceptable, although there were concerns about the rigour of informed consent. Heterosexual participants' criticism of people from higher prevalence groups for HIV declining tests, while maintaining their own right to opt-out, suggested that attitudes towards testing may be influenced by levels of perceived risk.
HIV testing	Wilson, 2017	All groups recognized tensions around adolescent autonomy in the absence of clear consent guidelines. Adolescents valued support people during testing but wanted autonomy over testing and disclosure decisions. Health care workers felt pressured to defer consent to caregivers. Caregivers wanted to know results regardless of adolescents' wishes.
HIV testing (maternal)	Aarnio, 2009	<p>Male partners are decision-maker, spousal approval needed for informed choice, want targeted information (based on education level, weak ART/PMTCT infrastructure, religious customs)</p> <p>Perceptions of HIV in pregnancy women particularly vulnerable to HIV due to their limited income opportunities, forcing unmarried and married women alike to transactional sex - limiting their chances to prevent HIV.</p> <p>Perceptions of husbands' involvement in antenatal VCT Means of male involvement: Most survey participants supported provision of antenatal VCT, but only few perceived husbands to benefit directly Participants emphasized the importance of prior agreement of antenatal HIV testing. Testing without husband's consent was equivalent to abandoning the code of sharing and respect in marriage, and could lead to divorce and inability to disclose results. Controversially, hiding the results could also mean divorce. Men considered HIV issues to be secrets for wife and husband only. Pregnancy could not trigger discussion on HIV. Husbands were best involved in antenatal VCT through couple counseling, which gave the couple hope, encouragement to stay faithful, better understanding of the information, and a fair basis for planning the future. Receiving positive results alone could result in unfair blame and divorce. The husband was involved if the pregnant wife was found HIV-positive. For most survey participants, involvement meant being openly informed and taking the HIV test.</p> <p>Barriers to male involvement: Reluctance to learn one's HIV status, grounded in the fear of HIV, shame, divorce and losing hope, feeling of no risk, and men's stubborn nature A weak marriage undermines the whole concept of male involvement, such as resulting in the lead to husband denying his wife the test, unhappy marriage, or divorce Perceived health services, including ANC, as women's area, and shameful for husbands to attend</p> <p>Support to male involvement: If disclosure of HIV-positive results to partner was assisted by health personnel, family or friends, less divorces would occur, and more husbands would test</p>
HIV testing (maternal)	Angotti, 2011	<p>1.HIV testing during antenatal care was perceived to be compulsory for pregnant women in rural Malawians. (no right to refuse testing, testing should be done if individual does not explicitly opt out)</p> <p>2.Many respondents considered the benefits of antenatal testing more important than choice. However, people may avoid government hospitals for antenatal services and turn to traditional birth attendants to escape what they perceived to be a mandatory testing requirement.</p> <p>3.Some husbands objected to their pregnant wives being tested is also significant.</p>
HIV testing (maternal)	Baxter, 2000	Women positive for HIV test offer but less uptake. Support in the form of information, together with social support, eases the anxiety associated with the HIV test, and gives some women the confidence to test in order to protect their babies from possible infection. Most stated that they were happy to be tested for HIV as part of normal routine procedure. However, a significant minority said that they needed to give explicit consent prior to the HIV test being carried out.

HIV testing (maternal)	Bulman, 2013	In Canadian provinces with opt-out policies for maternal HIV screening, pregnant women are told HIV screening is routine and are provided with the opportunity to refuse. Women have difficulty obtaining clear information about maternal HIV screening, are often not told they have the right to refuse maternal screening (do not have opportunity or option to give consent/refuse the test), and experience paternalism from physicians.
HIV testing (maternal)	de Zulueta, 2007	<ol style="list-style-type: none"> 1. Routine screening combined with professional recommendation may be successful in increasing uptake, but may be at the cost of eroding informed consent (people felt pressured to accept testing against their will, one person consented despite poor English understanding); 2. Protecting third parties from preventable disease may outweigh the moral duty of respecting autonomy; 3. Screening policy should be made transparent for women seeking antenatal care
HIV testing (maternal)	Madhivanan, 2014	While all of the HIV-positive women in the study received HIV and PMTCT services at a government hospital or antiretroviral therapy center, almost all reported attending a private clinic or hospital at some point in their pregnancy. According to the participants, HIV testing often occurred without consent (power differential made no allowance for patient autonomy esp for rural women, little information on risk/benefit of procedures); there was little privacy; breaches of confidentiality were commonplace; and denial of medical treatment occurred routinely. Among women living with HIV in this study, violations of their human rights occurred more commonly in private rather than public healthcare settings
HIV testing and care	Castro-Vasquez, 2007	Latin American men in Japan received information concerning medical treatment, but they were advised neither about alternative treatments nor about the feasibility of seeking a third party's advice. Informed consent and communication between the informants and physicians were obstructed by language and structural, as well as cultural barriers. Despite official initiatives and financial rewards to enhance consensual medical treatment, this ethnographic study suggested that poor levels of communication reduced informed consent to a mere provision of information. Moreover, for the informants, the inability to use freely medical records as well as the restrictions imposed by the use of suggested hospitals largely contradict the principle of consent.
HIV testing and care	Feyissa, 2012	Testing and disclosing test results without consent, designating HIV clients, and unnecessary referral to other healthcare institutions and refusal to treat clients were identified. From the FGDs, participants expressed the existence of frequent discriminatory actions against PLHIV amongst healthcare providers. This pertained to unnecessary referral of, and designating of PLHIV, testing and disclosure of the test results without getting informed consents and refusal to treat HIV clients.
HIV/STI partner notification	Adams, 2015	Moderate acceptability of HIV/STI disease notification. Challenges included; maintaining confidentiality in a small island; public perception that confidentiality was poorly maintained; fear and stigma; testing might be deterred; reporting may not occur; enacting legislation would be difficult; and opposition by some opinion leaders. For PN, contract referral was the most acceptable method and provider referral the least. Contract referral unlike provider referral was not "a total suspension of rights" while taking into account that "people need a little gentle pressure sometimes". Extra counselling would be needed to elicit contacts or to get patients to notify partners. Shame, stigma and discrimination in a small society may make PN unacceptable and deter testing. With patient referral procrastination may occur, and partners may react violently and not come in for care. With provider referral patients may have concerns about confidentiality including neighbours becoming suspicious if a home visit is used as the contact method. Successful contact tracing required time and effort. With contract referral people may neither inform contacts nor say that they did not. Strategies to overcome barriers to DN and PN included public education, enacting appropriate legislation to allow DN and PN, good patient counselling and maintaining confidentiality.

HPV vaccination	Batista Ferrer, 2016	HPV vax access could be affected by differing levels of commitment by school staff, school nurses, parents and young women to ensure parental consent forms were returned. Literacy and language difficulties undermine informed consent and may prevent vaccination.
HPV vaccination	Brabin, 2007	Parents with views consistent with support for adolescent autonomy wanted to encourage responsible behavior (if well-informed/mature), protect children from ill-informed or bigoted parents, and respected confidentiality/privacy and individual rights. Other parents insisted on being involved in decision making, emphasizing adult responsibility for a child's health and guidance (paternalism), erosion of parental rights, and respect for cultural and moral values. Other parents wanted clearer legal definitions governing parental rights and responsibilities (age guideline) or hoped for joint decision-making
HPV vaccination	Brown, 2010	The prevailing theme of new communication challenges was identified and these were connected to the activities of (i) explaining, (ii) consenting and (iii) managing conflicts between parents and their children with respect to vaccination decisions. The importance of decisions being fully informed was emphasized and concern was expressed about the adequacy of the information provided to girls and their parents in schools. Whether consent would be granted by the parent or by the child and how potential disagreements should be managed remained ambiguous. Participants considered it appropriate to offer the vaccine without parental consent if other criteria, such as an assessment of competency, were met.
HPV vaccination	Bunton, 2013	Disliked lack of information or confusion about vaccine. Informed consent was formal, not substantive (lack of information, marketing/pushing/selling vaccine vs providing detailed comprehensible information)
HPV vaccination	Chang, 2018	Decision-making regarding initiation of the human papillomavirus (HPV) vaccine series (who made the final decision) - More than half of the dyads did not agree on who made the decision to start the vaccine. Most adolescents and parents described a similar account about when they were offered the HPV vaccine, although the interpretation of the event in terms of the decision-maker might have differed. More than half of adolescents and parents individually mentioned the health care provider in their description of the HPV vaccine decision-making process even though they were not queried about the role of the provider. Need to balance adolescent autonomy with parental involvement.
HPV vaccination	Gottvall, 2015	The school nurses were convinced that parental consent was needed for HPV vaccination of 11-year-old girls, but problems identified were the difficulty to judge when a young person is to be regarded as autonomous and what to do when children and parents do not agree on the decision. A solution suggested was that obtaining informed consent in school nursing should be seen as a deliberative process, including the child, the parents and the nurse. The nurses described how they were willing to strive for a dialogue with the parents and negotiate with them in the consent process. Seeing autonomy as relational might allow for a more dialogical approach towards how consent is obtained in school-based vaccination programs. Through such an approach, conflicts of interests can be made visible and become possible to deal with in a negotiating dialogue. If the school nurses do not focus exclusively on accepting the individual parent's choice, but strive to engage in a process of communication and deliberation, the autonomy of the child might increase and power inequalities might be reduced. Issues with time-consuming consent process, cultural/language barriers (immigrant parents did not return consent form)

HPV vaccination	Stretch, 2009	School nurses knew how to assess the competency of under-16s but were still unwilling to vaccinate if parents had refused permission. If parents had not returned the consent form, school nurses were willing to contact parents, and also to negotiate with parents who had refused consent. They seemed unaware that parental involvement required the child's consent to avoid breaking confidentiality. Nurses' attitudes were influenced by the young appearance and age of the school year group rather than an individual's level of maturity. They were also confused about the legal guidelines governing consent. School nurses acknowledged the child's right to vaccination and strongly supported prevention of HPV infection but ultimately believed that it was the parents' right to give consent. Most were themselves parents and shared other parents' concerns about the vaccine's novelty and unknown long-term side effects. Rather than vaccinate without parental consent, school nurses would defer vaccination.
HPV vaccination	Wilson, 2012	All public health units request parental consent for students to receive the HPV vaccine and 5/36 also request or encourage student consent; 14 health units indicated they would immunize a grade 8 girl at a school clinic, in the absence of parental consent, if the student requested immunization and was judged capable of providing informed consent.
HPV vaccination	Wood, 2011	When there is a difference of opinion between daughters and parents or guardians about giving the HPV vaccine, stakeholders felt that overriding the parents' wishes was problematic and could damage the relationship between school and parents. A number of practical problems were raised in relation to establishing whether parents were genuinely against their daughter receiving the vaccine. Although many respondents recognized that the Gillick guidelines were relevant in establishing whether a girl could provide consent herself, they still felt that there were significant problems in establishing whether girls could be assessed as Gillick competent. In some areas school nurses had been advised not to give the vaccine in the absence of parental consent. None of the respondents suggested that a girl should be vaccinated against her consent even if her parents wanted her to have the vaccine
HSV-2 testing	Cham, 2016	<ol style="list-style-type: none"> 1. Overall, parents were supportive of HSV-2 testing, which they thought was a beneficial sexual health resource for adolescents and parents, and a motivation for parent-child communication about HSV-2, sexual activity and sexual abuse. 2. Issues with returning test results: Some parents supported the proposed plan to disclose HSV-2 test results to adolescents only, citing the importance of adolescent privacy and the possibility of HSV-2 positive adolescents being stigmatized by family members. Conversely, opposing parents requested parental access to results. These parents were concerned that adolescents may experience distress following a positive result and withhold this information thereby reducing parents' abilities to provide support. 3. Parents were also concerned about support for victims of sexual abuse.
Infertility	de Vries, 2009	Although physicians and parents agreed that infertility would have a major impact on the future quality of life, they sometimes disagreed on whether the topic should be discussed with adolescents. Physicians always wanted a separate discussion with adolescents because of the sensitive nature and the experience that parents sometimes misjudged the stage of maturity of their son. Parents, however, wanted control over whether physicians discussed the topic with their child and what was said. Physicians did not accept this control and, when necessary, were willing to bypass the parents and discuss the topic with the adolescent even when parents refused consent
Mammography screening	Osterlie, 2008	<ol style="list-style-type: none"> 1. Mammography was seen as overcoming a "threshold mile" - Even though the women acknowledged breast cancer as a serious disease, there was a mutual understanding that it was tempting to postpone tasks they ought to do, including mammography 2. Women were grateful for being called in/invited as this made the decision making process easier and others had taken control and made the decision for them.

Maternity care	Newnham, 2017	This study describes practices around the gaining of consent for an epidural in labour, juxtaposed with similar processes relating to use of water for labour and/or birth. Women were not given full disclosure of either practice and midwives tailored the information they gave according to the institutional policies rather than evidence. Epidural information is scant and consent is brief, often verbal, with women not required to understand the a full list of side-effects or possible risks, and water use is fraught with risky language, is not offered freely as an option, and consent is written, rigorous, and psychologically arduous in its explications of risk. Informed consent is an oft-cited human right in health care, yet in maternity care the micro-politics of how informed consent is gained is difficult to ascertain, leading to a situation whereby the concept of informed consent is more robust than the reality of practice; an illusion of informed consent exists, yet information is often biased towards medicalised birth practices.
Maternity care	Nicholls, 2019	Four themes were identified: 1) Choice and shared decision-making. Pregnant women do not always experience consent in a choice-making way and often do not understand information provided to them. 2) Contextualising information disclosure. What is important to women is not only the information but the relational context in which consent is obtained. 3) Quality of HCP-woman relationship. Trust in their healthcare professional sometimes makes women seek less information and conversely. Individualised information is desired by women but professionals found it difficult to ensure that women receive this in practice. 4) Law and professional practice. Doctors are more aware of legal developments in consent related to the Montgomery case than their midwifery colleagues, but they are not always certain of the implications.
Maternity care	Pafs, 2016	1. Unmet need for contraception and unintended pregnancies were common themes in women's narratives and appeared to influence the decisions women made about their pregnancy status. 2. Perceived need for treatment and quality of care. Symptoms throughout pregnancy, such as swollen feet, bleeding, pain or not feeling fetal movement, were seldom referred to as reasons to seek care. The women relied on, and sought advice from, their closest social network of family, friends, neighbors, CHWs, or traditional healers. However, among those with symptoms in early pregnancy, hesitation in both consulting others and seeking care were evident and described in the women's narratives about having thought or wished for the symptoms, mostly bleedings, to stop by itself. The shameful and stigmatizing label of being pregnant outside a partnership was a contributing reason, and these pregnancies were often kept secret. 3. Missing supplies, lack of staff, poor patient-provider interaction and suboptimal treatment, as described in the women's narratives, were identified as main barriers to an optimal care encounter. Repeated care-seeking occurred because women had either been misdiagnosed, received incomplete care, discharged too early, or received inappropriate treatment altogether. These were identified among women both in the early and late stages of pregnancy, and appeared to have contributed to some of the near-miss events. 4. Adherence to the use of traditional medicine was prominent in women's care-seeking during pregnancy, particularly right before birth. The "medicine" was taken in secret and seldom revealed to the healthcare providers because the women perceived that most biomedical health facilities would impose a fine if they found out.
Maternity care	Stapleton, 2002	1. Most women did not find leaflets helpful in decision making/informed choice 2. Most health professionals reported feeling pressured by time constraints, and women were often observed accommodating health professionals by limiting their questions. "informed compliance" instead of "informed choice" 3. Women sometimes made choices on the basis of their previous experiences of childbirth but were often met with resistance if their preferences contradicted established clinical norms. Women tended to comply with the suggestions of health professionals, and unless openings were made, they rarely instigated discussion about their own preferences. 4. Health professionals encouraged decision making towards technological intervention by conveying information which either minimised the risk of the intervention or emphasised the potential for harm without the intervention. This seemed to make it difficult for women to hear alternative messages, even from obstetricians. Fear of litigation promoted notions of "right" choices with which clinicians felt clinically secure and which they thought would afford them protection against litigation.

		5. There was a strong hierarchy within the maternity services, with obstetricians at the top, midwives and health professionals other than doctors in the middle, and pregnant women at the bottom. Women who experienced continuity of midwifery care were more likely to report trusting relationships in which they felt more able to ask questions. Such relationships, which were rarely encountered in this study, seemed to reduce imbalances in power and facilitate a partnership approach to maternity care.
Maternity care	Sumankuuro, 2019	Women's lack of autonomy to seek care without prior permission, perceived quality care of traditional birth attendants, stigmatisation of unplanned pregnancies and cultural beliefs associated with late disclosure of childbirth labour all delayed mothers timely use of skilled care in the study communities. These barriers compounded problems arising from communities that are geographically isolated from hospital care. Decisions about seeking maternal care were usually made by the expectant woman's husband and family without providing adequate support to pregnant women during the latter stages of pregnancy and delivery.
Maternity care	Walsh-Gallagher, 2012	Women with disabilities felt their ability to make choices and maintain control over their childbirth experiences was removed as the usual services were geared to provide for 'normal', able bodied women and were not adapted to their individual needs. Moreover, a proportion were offered a termination and, although all refused, they subsequently went on to indicate feeling pressurised to place their newborn babies into social services care.
Maternity care	Bluff, 1994	"they know best"/"they know better than I do" (no matter what happened during labor/birth process - high trust in midwife/doctor's expertise, professional training/knowledge), unquestioningly accepted decisions made by those whom they saw as professionals (position of power/authority, comply because of trust) regarding eating/drinking, place of birth, analgesia, epidurals; partner may support but often peripheral position compared with professional
Maternity care	Churchill, 2000	<ol style="list-style-type: none"> 1. Midwives were the primary source of information 2. Women felt encouraged to make an informed decision and took an active part in the decision making about their antenatal care. This is especially if they attended more than one type of clinic for antenatal care. 3. Women perceived high levels of informed decision-making, especially if they attended midwife/GP units. 4. Women having normal vaginal deliveries and elective cesarean section felt more encouraged to make informed decisions, as compared to those who had instrumental vaginal deliveries and emergency cesarean sections.
Maternity care (Assisted childbirth)	Ag Ahmed, 2018	Several participants recognized the value of assisted delivery but gave birth at home. They identified sociocultural determinants related to their representations and bodily experiences; the risks and emotions (fear, stress, anxiety) associated with pregnancy; the onset of labor and delivery; and their weak autonomy in terms of movement, decision-making, and economic agency. Nomadic women are not free in their movements, and in order to seek care, they require the permission and support of a man (husband, brother, or father). Furthermore, the participants are housewives, and men control family resources and make decisions regarding all financial matters. Assisted delivery is often only considered when there are complications.
Maternity care (childbirth decisions)	Nelson, 1983	Differences were found between informed patients & less informed patients with respect to background characteristics. Knowledgeable patients not inclined to assume a completely passive role in their medical care: they know a great deal about childbirth and are willing to express their opinions. Even well-informed clients may be willing to comply with the physician if it is simply suggested that her interests run counter to the interests of the child. Further, it was found that the more informed the obstetrical patient, the more likely she was to consider alternatives to the hospital routines, & that the expression of desires for alternatives did not result in different treatment by MDs. The concept of a negotiated illusion of autonomy is introduced to explain how the relationship between a highly informed patient & her MD was managed by both parties so that compliance was assured without dissatisfaction or disruption of the relationship.

Maternity care (c-section vs vaginal delivery)	Kingdon, 2009	<p>Whilst many women supported the principle of choice, they identified how, in practice their autonomy was limited by individual circumstance and available care provision. All women felt that concerns about their baby's or their own health should take precedence over personal preference. Moreover, expressing a preference for either vaginal or caesarean birth was inherently problematic as choice until the time of delivery was neither static nor final. Women did not have autonomous choice over their actual birth method, but neither did they necessarily want it.</p>
Maternity care (c-section vs vaginal delivery)	Moffat, 2007	<p>Evolution of decision-making</p> <ol style="list-style-type: none"> 1. Women's early thoughts about the delivery were strongly influenced by their experience of their previous delivery 2. There was development of the decision during pregnancy, with most women acknowledging that a decision could never be final because medical and social circumstances might change <p>Women's participation and involvement in decision-making</p> <ol style="list-style-type: none"> 1. All the women expressed a desire to be involved in the process of decision making, but not all of them actively participated. 2. Most women felt happy with their involvement and level of responsibility 3. Women varied in the level of confidence they felt about decisions they had made <p>Factors affecting decision-making</p> <ol style="list-style-type: none"> 1. Previous delivery 2. The desire to have a 'normal' delivery was expressed in different ways; as the wish to experience a natural birth 3. Practical implications of the different modes of delivery for their recovery. (temporary inability to drive, family life disruption because longer recovery period after C-section) 4. Information received (quantity) 5. Sources of influence (health professional) <p>Feelings about the amount and quality of the information received regarding delivery options varied greatly, with many women wishing for information to be tailored to their individual clinical circumstances and needs. In contrast to the impression created in the media, there was no evidence of clear preferences or strong demands for elective caesarean section</p>
Maternity care (c-section vs vaginal delivery)	Abdillahi, 2017	<p>Healthcare providers were often prevented from performing emergency cesarean delivery until the required consent had been received from the woman's extended family. Of the 138 maternal near misses and deaths recorded, 50 (36%) were associated with emergency cesarean delivery.</p>
Maternity care (induction)	Jay, 2018	<p>Information from midwives and antenatal classes was minimal, with family and friends cited as key informants. Midwives presented induction as the preferred option, and alternative care plans, or the relative risks of induction versus continued pregnancy, were rarely discussed. Women reported that midwives often appeared rushed, with little time for discussion.</p>
Maternity care (induction)	Moore, 2014	<p>Five major themes from the preinduction interview were identified; safety of baby, women's trust in their clinician (info/rationale), relief of discomfort and/or anxiety, diminish potential or actual risk, and lack of informed decision making. Five major themes were identified from the postinduction interview; lack of informed decision making (unable to describe process, medications used, risks, options; told that IOL was needed/recommended with no/minimal information), induction as part of a checklist, women's trust in their clinician, happy with induction, and opportunities to improve the experience.</p>

<p>Maternity care (Maternal-fetal surgery for myelomeningocele (MMC) and fetal intervention) for congenital diaphragmatic hernia (CDH).</p>	<p>Blumenthal-Barby, 2016</p>	<ol style="list-style-type: none"> 1. Risks associated with the conditions of MMC and CDH were communicated more often qualitatively (70%) than quantitatively (30%); mortality more often discussed quantitatively vs likelihood of survival 2. Risks and benefits were discussed consistently across doctors and patient conditions. 3. Doctors spent significantly more time talking during the consultations; on average, 85% of consultations consisted of physicians talking compared to 15% by patients 4. Patients' primary mode of participation in consultations was through posing questions to physicians (clarify diagnostic or surgical procedures) 5. Patients who asked more questions received more detailed information with which to better inform their decision. There are six domains of questions: (i) diagnostic clarification, (ii) lifestyle changes, (iii) managing risks, (iv) quality of life concerns, (v) surgical procedure clarification, and (vi) termination concerns.
<p>Maternity care (place of birth)</p>	<p>Bedwell, 2011</p>	<ol style="list-style-type: none"> 1. Little or no discussion between couples when making a choice of place of birth "decided subliminally" 2. Hospital birth was seen as the 'norm' and partners expressed an opinion that suggested that to disrupt the 'status quo' was unjustified. 3. Although decisions regarding hospital birth were accepted without discussion, when asked about birthplaces other than hospital, expectant fathers indicated that they would want some sort of discussion before reaching a decision 4. Acknowledged that their partner was the primary focus and therefore had a slightly better bargaining position in any decision making. Yet although they stated that their partner should have the 'final say', they were open about the persuasive words that they would use if the decision opposed their own. 5. The desire for their baby to be born in hospital was motivated by the need to protect their partner from harm 6. Their views were also influenced by their perception of health professional roles 7. Many men had concerns about their ability to cope when their partner was in labour; they viewed the hospital and staff as a means of protection
<p>Neonatal care</p>	<p>Brinchmann, 2002</p>	<ol style="list-style-type: none"> 1. Indecision and uncertainty (ambivalence) - Most parents would want their child to live, whatever the case, and would choose treatment at any cost. Others wanted to participate and join in the decision making, but at the same time it was good for them to be spared from making the choice 2. Information and communication - most parents emphasized that it is the health professionals who are responsible for these decisions and who have the necessary medical knowledge and experience. Several of the informants stressed that good personal communication takes time. 3. Participate but do not decide - parents lack the necessary knowledge and experience; they would not be rational, but would let their feelings take over. The parents would be in shock or in crisis, so they would not be capable of making rational decisions. 4. Parents should be well informed, included in the discussion, and listened to. The professionals have the responsibility, but parents need to feel that they are being taken seriously 5. Parents know themselves best and know best how they would be able to cope - parents' observations and points of view must thus be taken seriously. Moreover, adult patients have the right to decide for themselves, and that in other situations the opinions of close relatives are given weight when they are not capable of deciding for themselves. The question was raised concerning why neonatal medicine is different to other areas of medicine in this respect. 6. The situations and the people involved in them were very varied in terms of the health professionals, the infants and their parents. What is wrong and what is right had to be determined individually in each particular situation.
<p>Neonatal care</p>	<p>Den Boer, 2019</p>	<ol style="list-style-type: none"> 1. NICU providers regard prospective consent as the most preferable approach, but deferred consent approach is also needed; 2. Ethical considerations for deferred consent and parental autonomy concerns NICU providers; 3. NICU providers with previous experience reported positive experience with deferred consent, attributing to good communication and timing of approach to parents

Newborn screening	Campbell, 2005	<p>1. Data suggest parental ignorance remains widespread even when consent is required for newborn screening;</p> <p>2. One may get a more informed decision if information regarding all screening and testing in newborns were raised with parents during pregnancy so that they had more time to make an informed decision even when consent is required for newborn screening</p>
Newborn screening	Detmar, 2007	<p>Parents were not well informed and see screening as mandatory (hardly any parents objected to the fact that screening is more or less automatic and that consent is not explicitly requested, unaware that they could refuse the heelprick, participation seen as natural healthcare encounter, prefer opt-out consent approach), parents would like to be informed early (e.g. during pregnancy) if heelprick program are to be expanded</p>
Newborn screening	Cusworth-Aerts, 2007	<p>(1) Knowledge and awareness of initial newborn screening information. Parents knew little about newborn screening. Providers assumed that the absence of questions from patients about newborn screening reflected a lack of interest. Few providers were aware of the specifics of newborn screening in their states.</p> <p>(2) Knowledge and understanding of the process of informing parents and providers of the results of newborn screening. Most parents preferred to be given screening results by their own providers and only if there was a problem. Parents who received requests for retesting from the health department were often alarmed and confused because they were not aware of the possibility of retesting or the state's involvement. Only clinicians who provided postnatal care received test results; some felt that test result reporting was too slow. Screening professionals identified parents' failure to designate a primary care provider as a barrier to reporting results, requiring the health department to contact parents directly when retesting was needed.</p> <p>(3) Informed consent and costs. Most parents were not concerned about consent or costs. Most providers and screening professionals felt that requiring parental consent would decrease test uptake. Providers were unaware of the costs of screening and who paid.</p> <p>(4) Recommendations for how newborn screening information needs to be communicated to parents. All groups agreed that education about newborn screening would best be communicated by the primary prenatal care provider during routine visits in the third trimester, accompanied by a concise brochure in the woman's first language.</p> <p>(5) Recommendations for what parents and providers want and need to know. Both parents and providers felt that parents initially need only limited information about newborn screening: that screening will be done, that it will benefit their baby, that retesting is a possibility, and how parents will be notified of results. Providers and screening professionals agreed that providers do not require detailed education about screening but do need resources for additional information for themselves and parents.</p>
Newborn screening (PKU, CHT, cystic fibrosis, DMD)	Parsons, 2007	<p>Information giving about newborn screening was reported to be ad hoc, with most women receiving information in the postnatal period. Mothers talked about newborn screening as a routine procedure that 'had' to be done. There was some recognition that consent for screening should have been given, but this was often compromised because the test was being offered by a trusted health professional and a social expectation that responsible mothers should have their babies tested.</p>
Newborn screening (PKU, DMD)	Campbell, 2003	<p>Respondents across racial groups support mandatory newborn screening for treatable conditions like phenylketonuria (PKU), citing lack of parental knowledge, and concerns about immature parental decision-makers. Parents do, however, want more information. Citing a variety of psychosocial concerns, respondents believe that parents should have access to predictive genetic testing for childhood onset conditions, even when there are no proven treatments. Respondents want this information to make reproductive and non-reproductive plans and decisions. Although respondents varied in their personal interest in testing, overwhelmingly they believed that the decisions belong to the parents.</p>
Post-rape care	Wangamati, 2016	<p>Health providers showed little regard for informed assent, confidentiality, and privacy while offering postrape care to adolescent girls.</p>

Pregnancy testing	CRR, 2013	Coerced and forced pregnancy testing in schools leads to exclusion and expulsion of pregnant students, although this is not supported by Tanzanian law. Coercive testing is problematic because consent is not voluntarily or freely given—this is because pregnancy testing is required as a precondition for admission to school. Although a student could technically refuse to undergo a pregnancy test, in many cases doing so would leave her with no meaningful alternative for her education.
SRH services (general)	Dean, 2017	Disabled women's recognition of their rights and ability to control their own sexuality are unevenly constrained due to intersectional gendered power relation
SRH services (general)	Iriane, 2019	This paper explores doctors' treatment decisions made without parental consent when managing adolescents presenting with sexual and reproductive health issues. Generally, doctors weigh any decision by examining the health risks and benefits involved. While fear of litigation influences treatment decisions, a strong adherence to the ethical duty of 'do no harm' outweighs other considerations (e.g. legal duty, culture - though fear of legal consequences was reported as an influence on doctor's decisions when managing adolescent issues). When all options are risky, choosing what is considered 'the lesser of two evils,' i.e., what is perceived to be in the best interest of the adolescent, is adopted. The complexity of a medical decision related to adolescent SRH issues is increased further when legal requirements are not in synch with the ethical and personal values of doctors.
SRH services (general)	Jafarey, 2005	General acceptance of shifting "informed consent" focus from individual patient (easiest when there is direct communication with the individual) to family members OR attending physician - ethical dilemmas for providers (uncomfortable with communication which excludes the patient, paternalistic primary decision making role), physician's duty to bring patient into decisionmaking process (no consensus on how to identify essential info vs "details" that could be omitted, issue of withholding info voluntarily, exclude "more distressing" facts about disease or give "more optimistic" picture to ensure cooperation for procedure). Need time and patience especially with tiered process. Obstetrics - women may not make decisions unless husbands present, may even be happier leaving decision entirely to spouses, willingly assuming backseat
STI screening	Avuvika, 2017	Adolescent girls and young women in Mombasa, Kenya expressed willingness to participate in STI screening. A major incentive for screening was participants' desire to know their STI status, especially following perceived high-risk sexual behavior. Lack of symptoms and fear of positive test results were identified as barriers to STI screening at the individual level, while parental notification and stigmatization from parents, family members and the community were identified as barriers at the community level.
STI screening (internet)	Gilbert, 2017	The study identified three main themes: i) the meaning of informed consent (consent page viewed as important and for protection of individual and organization/legal requirements; participants demonstrated varying understandings of specific components); ii) the impact of previous experience on understanding informed consent (participants understood difference between online and in-person testing; IC concepts were better understood by participants with more in-person testing experience); iii) the role of website design on achieving informed consent (design of page to disrupt speedy click-throughs was valued and demonstrated seriousness of the consent page)
Surrogacy	Tanderup, 2015	None of the 14 surrogate mothers were able to explain the risks involved in embryo transfer and fetal reduction. The majority of the doctors took unilateral decisions about embryo transfer and fetal reduction. The commissioning parents were usually only indirectly involved. In the qualitative analysis, difficulties in explaining procedures, autonomy, self-payment of fertility treatment and conflicts of interest were the main themes.

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