

Appendix 3 - Supplementary table of included studies, including alignment with the identified six themes and major findings

Study, Country	Year	Study type	Research methodology, data analysis	Participant information (number, age, gender)	Aim	Themes						Major findings	
						1 ^a	2 ^b	3 ^c	4 ^d	5 ^e	6 ^f		
Aman et al. [54] USA	2007	Quantitative	Survey evaluation of information booklets written at 4 th -5 th grade reading level with illustrations, explaining patient rights and responsibilities, and medication information. Chi-square and phi coefficients.	N=604 people with (n=456) and without intellectual disability (n=372). Aged 8-84 years. 320 women.	Assess effect of booklets in improving understanding and increasing knowledge about patient rights, responsibilities, and medications.		•	•				•	<ul style="list-style-type: none"> • Booklets were well-received and improved patient knowledge about medications and patient rights. • Most participants involved a support person to help read and understand information.
Sowney and Barr [59] UK	2007	Qualitative	Focus groups of nurses in the emergency department who have provided care to adults with intellectual disability. Colaizzi's procedural steps.	N=27 nurses. Unspecified age and gender	Explore challenges experienced by nurses when providing care to adults with intellectual disabilities, focusing on communication and valid consent.		•		•			•	<ul style="list-style-type: none"> • Time constraints, unfamiliarity with patients, and lack of training affected consent processes. • Many nurses were unfamiliar with UK consent guidelines. • Some participants believed that proxy consent was appropriate and necessary.
Carlson et al. [69] UK	2004	Quantitative	Surveys to professionals about current practices of informed consent when referring to a community intellectual disability service. Descriptive analysis.	N=79 professionals that care for people with intellectual disability. Unspecified age and gender.	Investigate current practices of informed consent for referral to a community learning disability service.		•	•		•		•	<ul style="list-style-type: none"> • Many professionals were unfamiliar with consent guidelines. • Proxy consent was used by some as an alternative.
Ferguson and Murphy [55] UK	2014	Quantitative	Provision of in-person training sessions about medications for people with intellectual disability, and assessment of their ability to make informed decisions. Pearson's correlations, Fisher's exact test.	N=28 adults with intellectual disability. Aged 20-56 years. 10 women.	Assess the impact of medication training sessions on the capacity of people with intellectual disability to make informed medication decisions.			•				•	<ul style="list-style-type: none"> • Information training sessions may improve knowledge to assist with informed consent.
Ferguson et al. [60] UK	2010	Qualitative	Face-to-face semi-structured interviews with people with intellectual disability and their carers, and focus groups with physiotherapists. Thematic analysis.	N=21 adults (n=4 with intellectual disability, n=13 carers, n=4 physiotherapists). Unspecified age and gender.	Explore the health choices and perspectives of people with intellectual disability, their carers, and physiotherapists at a hydrotherapy service.		•	•	•			•	<ul style="list-style-type: none"> • Carers were both enablers and barriers to informed consent for hydrotherapy. • Some physiotherapists and carers questioned the capacity of people with intellectual disability or overrode their choices.
Fisher et al. [61] USA	2005	Qualitative	Face-to-face semi-structured interviews of directors of community service agencies that provide care for people with intellectual disability. Thematic analysis.	N=13 directors of community service agencies. Unspecified age and gender.	Explore the perspectives of directors of community service agencies about healthcare decision-making for people with intellectual disability.		•		•				<ul style="list-style-type: none"> • Proxy decision making was common and sometimes overrides the consent of the person with intellectual disability. • Inconsistent informed consent practices were described.
Fish et al. [56] UK	2017	Qualitative	Easy read questionnaire about medication co-produced with a consultation group distributed to self-advocates. Thematic analysis.	N=58 self-advocates with intellectual disability. Unspecified age and gender.	Explore the perspectives of people with intellectual disability about medication information currently being provided in healthcare.		•	•	•	•		•	<ul style="list-style-type: none"> • People with intellectual disability do not find current practices of medication information helpful. • Medication information should be accessible and tailored to the individual. • Health professionals should make reasonable adjustments to support medication informed consent.

Goldsmith, et al. [63] UK	2013	Qualitative	Observation of people with intellectual disability receiving a blood test, and semi-structured interviews with people with intellectual disability about their experiences of blood tests. Inductive thematic analysis.	N=20 adults with intellectual disability (n=6 observed having a blood test, n=14 interviews about their experience). Age 27-64 years. Unspecified gender.	Examine the informed consent process for blood tests from adults with intellectual disability and explore their experiences with blood tests.	•	•									<ul style="list-style-type: none"> • Informed consent was not properly obtained. • Provided health information was not accessible. • Training is needed to ensure consent is person-centered and tailored for people with intellectual disability.
Graham et al. [57] UK	2020	Qualitative	Semi-structured interviews with pharmacists about the impact of a pharmacist specialized in holistic medication prescription. Inductive thematic analysis.	N=9 individuals who provide care for people with intellectual disability (n=6 health professionals, n=3 carers) Unspecified age. 9 women.	Evaluate the impact of pharmacist independent prescribers in supporting people with intellectual disability, including the provision of medication education.		•									<ul style="list-style-type: none"> • Health professionals need additional training when providing care to people with intellectual disability. • Health staff need to consider acquiescence when obtaining informed consent.
Hall et al. [64] UK	2011	Quantitative	A virtual reality experience that explores a hospital environment to convey healthcare information and support informed consent. Cognitive interviews then assessed participant memory and gained healthcare knowledge. Inductive and deductive thematic analysis.	N=20 people with intellectual disability. Aged 20-80 years. 9 women.	Assess a virtual reality experience as a potential way to provide healthcare information to people with intellectual disability about healthcare.			•								<ul style="list-style-type: none"> • Virtual reality could be used as a multimodal format to convey health information to support informed consent.
Hart [65] UK	1999	Qualitative	Interviews of people with intellectual disability about their experiences after an admission in hospital that involved informed consent. Grounded theory analysis, constant comparative analysis.	N=13 adults with intellectual disability. Aged 28-49 years. 5 women.	Examine the experiences of people with intellectual disability with informed consent and decision-making while admitted in hospital.		•									<ul style="list-style-type: none"> • Inconsistent and inadequate consent practices were described. • Health professionals need more training in informed consent.
Hoglund and Larsson [68] Sweden	2019	Qualitative	Focus group and semi-structured interviews with midwives about their experiences providing care to women with intellectual disability, including sexual health, contraceptive counselling and informed choice. Content analysis, paradigm model.	N=19 midwives. Unspecified age and gender.	Explore the perspectives, experiences, and ways in which midwives provide contraceptive counselling and support informed choice in women with intellectual disability.		•	•		•						<ul style="list-style-type: none"> • Midwives want more training and support in informed consent for people with intellectual disability. • Reasonable adjustments can support informed consent, but there are no national guidelines about this. • Communication should be tailored and accessible.
Huneke et al. [58] UK	2012	Qualitative	Questionnaires (easy read and picture symbols) to assess the current practice of medication information and informed consent for individuals with intellectual disabilities. Descriptive statistics.	N=45 individuals with intellectual disabilities. Mean age 51.5 years, no range provided. 25 women.	Evaluate medication information provided to people with intellectual disability and assess whether there is sufficient accessible information to make informed decisions.		•	•		•						<ul style="list-style-type: none"> • Accessible information is needed. • Doctors need to improve communication skills and tailor their approach to informed consent, such as by checking understanding.
McCarthy [52] UK	2010	Mixed methods	Semi-structured interviews with women with intellectual disabilities about contraceptive decision-making. Postal questionnaires sent to general practitioners to explore their practices in prescribing contraceptives to women with intellectual disability. Multi-staged narrative analysis, content analysis.	N=23 women with mild or moderate intellectual disabilities, aged 20-51 years. N=162 general practitioners of unspecified age or gender.	Explore the current practice of prescribing contraceptives for women with intellectual disability (including informed consent), from the perspective of the patient with intellectual disability and general practitioners.		•	•	•	•	•					<ul style="list-style-type: none"> • Health professionals are unfamiliar with legal consent requirements and use proxy consent inappropriately. • Support people can both aid and exclude people with intellectual disability in consent. • Reasonable adjustments can aid informed consent. • Doctors and people with intellectual disability appear unaware of patients' right to accessible information.

Rogers et al. [62] Ireland	2020	Qualitative	Semi-structured interviews with clinical psychologists who work with adults with intellectual disability about their perspectives, experiences, and current practices in decision-making with patients with intellectual disability. Thematic analysis.	N=15 clinical psychologists working with adults with intellectual disability. Unspecified age. 12 women.	Explore key issues in decision-making capacity and autonomy in psychology when working with adults with intellectual disability.	•	•	•	•	•	•	<ul style="list-style-type: none"> Health information should be multimodal. Health professionals perpetuate discriminatory stereotypes and assume incapacity of people with intellectual disability. Family and carers can override or influence informed consent. Consent should be an ongoing process. 	
O'Dell et al. [66] USA	2012	Quantitative	Questionnaire for adults with intellectual disability about their healthcare interactions with providers and their healthcare perspectives. Descriptive statistics.	N=19 adults with intellectual disabilities Aged over 18 years. 12 women.	Explore the perspectives of adults with intellectual disability about their healthcare interactions, focusing on communication barriers and decision-making.	•					•	•	<ul style="list-style-type: none"> Communication barriers and assumptions of incapacity were not perceived by people with intellectual disability. Most (53%) felt their doctors would respect their decisions. Almost half (47%) felt unsure or that they didn't have control over their healthcare choices.
Rose et al. [70] UK	2013	Qualitative	Questionnaire to evaluate and collect feedback about a consent form for referral to a dementia service for adults with intellectual disability. Feedback was used to improve the form and the revised form was assessed again and compared to the original. Thematic analysis.	N=16 adults with intellectual disability Aged 20-63 years. 6 women.	Evaluate a consent form for adults with learning disabilities who are referred to specialist learning disability dementia services and improve the form with input from end-users.		•						<ul style="list-style-type: none"> Ways to improve accessibility of consent forms include pictures, added detail, reduced text volume, and a summary page.
Walmsley et al. [71] UK	2016	Qualitative	Semi-structured interviews with women with intellectual disability about their contraceptive decision-making process. Thematic analysis.	N=19 adults with intellectual disabilities. All women. Unspecified age.	Explore the experiences of women with intellectual disabilities about contraception decision-making, provision of information, and support provided by health professionals.	•	•	•	•				<ul style="list-style-type: none"> Insufficient and inaccessible health information is being provided to make a contraceptive decision. Proxy consent and coercion were described by women with intellectual disability. Consent should be a process.
Wiseman and Ferrie [72] UK	2020	Qualitative	Easy Read questionnaire with pictures about reproductive health were distributed to women with intellectual disability. Semi-structured focus group interviews were then conducted to explore reproductive health further. Thematic analysis.	N=21 women with intellectual disability (questionnaire) N=12 women with intellectual disability (focus group) Aged 18-78 years. All women.	To examine the experiences of women with intellectual disabilities in Scotland regarding their reproductive rights and health experiences.	•	•	•	•				<ul style="list-style-type: none"> Health professionals should not assume incapacity; they should advocate to support informed consent. Support people can act as both enablers and barriers to informed consent. There is a lack of accessible information available about contraception. Policies need to be updated to protect these rights.
Wood and Douglas [73] UK	2007	Mixed methods	Questionnaire for primary care practices about cervical screening for women with intellectual disability. Semi-structured interviews were conducted for select participants. Descriptive and thematic analysis.	N=20 questionnaires (10 general practitioners, 2 nurses, 6 managers, 2 administrative staff). N=6 interviews (2 general practitioners, 2 nurses, 2 managers). Unspecified age and gender.	To explore the views and current practices of primary care practices regarding cervical screening for women with intellectual disability	•	•		•				<ul style="list-style-type: none"> Most practices do not modify health information to make it accessible. There are communication barriers and a lack of training for health professionals. Health professionals want more guidelines about consent and caring for people with intellectual disability.

Arscott et al. [67] UK	1999	Quantitative	Assessments of verbal and memory ability, and capacity to consent to treatment using validated scales: the British Picture Vocabulary Scale (BPVS), the Rivermead Behavioural Memory Test for Children (RBMT-C), and the Ability to Consent Questionnaire (ACQ) One-way ANOVA, Scheffé's method, t-test, Pearson's correlations	N=40 adults with intellectual disability. Aged 20-57 years. 18 women.	To explore the relationship between verbal ability, memory ability, and the ability to provide informed consent in three different clinical vignettes.		•								<ul style="list-style-type: none"> Some questions and scenarios are more difficult to answer and can influence capacity to consent. Memory and verbal ability was correlated with ability to consent.
Ledger et al. [74] UK	2016	Mixed methods	Survey for professionals about their views and experiences in supporting women with intellectual disability to make contraceptive decisions. Descriptive and thematic analysis.	N=90 adults (23 nurses, 17 carers or support workers, 15 family members, 35 'others' including advocates, doctors, social workers, and academics). Unspecified age and gender.	To explore the views of third parties involved in contraceptive decision-making for women with intellectual disabilities.		•		•	•					<ul style="list-style-type: none"> There is insufficient accessible health information about contraception. A minority (38%) of women with intellectual disability made the final choice. Only 62% were involved in the medical discussion. Formal capacity assessments are rarely used or documented.
McCarthy [51] UK	2009	Qualitative	Semi-structured interviews were conducted with a woman with intellectual disability about their experiences with contraceptive decision making. Multi-staged narrative analysis, content analysis.	N=23 women with mild or moderate intellectual disability. Aged 20-51 years. All women.	To explore the choice and control of women with intellectual disability in their contraception healthcare choices, and the factors that contribute to their lack of autonomy		•	•	•		•	•			<ul style="list-style-type: none"> Health professionals lack adequate training. Support people can be barriers or enablers to informed consent. There are insufficient accessible resources to make contraceptive choices.

^aHealth Professionals' Attitudes and Lack of Education about Informed Consent.

^bInadequate Accessible Health Information.

^cThe Involvement of Support People.

^dSystemic Constraints within Healthcare Systems.

^ePerson-Centred Informed Consent.

^fEffective Communication between Health Professionals and Patients.