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## Characterising and monitoring preconception health in England: a review of national population-level indicators and core data sources

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### Abstract

Initiatives to optimise preconception health are emerging following growing recognition this may improve the health and wellbeing of women and men of reproductive age, and optimise health in their children. To inform and evaluate such initiatives, guidance is required on indicators that describe and monitor population-level preconception health. We searched relevant databases and websites (March 2021) to identify national and international preconception guidelines, recommendations and policy reports. These were reviewed to identify preconception indicators. Indicators were aligned with a measure describing the prevalence of the indicator as recorded in national population-based data sources in England. From 22 documents reviewed, we identified 66

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indicators across 12 domains. Domains included wider (social/economic) determinants of health; health care; reproductive health and family planning; health behaviours; environmental exposures; cervical screening; immunisation and infections; mental health, physical health; medication; and genetic risk. Sixty-four of the 66 indicators were reported in at least one national routine health dataset, survey or cohort study. Measures of preconception health assessment and care and assisted reproductive technology use were not identified in any current national data source. Perspectives from three (healthcare) professionals described how indicator assessment and monitoring may influence patient care and inform awareness campaign development. This review forms the foundation for developing a national surveillance system for preconception health in England. The identified indicators can be assessed using national data sources to determine the population's preconception needs, improve patient care, inform and evaluate new campaigns and interventions, and enhance accountability from responsible agencies to improve preconception health.

## Keywords

preconception; surveillance; indicators; reproductive health

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## Introduction

The health and health behaviours of women and men prior to pregnancy are key determinants of a successful pregnancy, and the health of women, men and their offspring in the short- and long-term.<sup>1, 2</sup> There is now ample evidence from developmental biology and epidemiological studies that improving preconception health represents an opportunity to reduce maternal and infant mortality and morbidity, prevent non-communicable disease in parents themselves and their offspring, and improve the overall health of at least two generations. The importance of optimal preconception health has been recognised in many national and international guidelines, position statements and policy reports. These provide clinical guidance on providing preconception care (PCC) to individuals planning pregnancy,<sup>3-9</sup> outline how primary care, maternity and community services may integrate PCC into existing services,<sup>5, 6, 9-12</sup> and call for continued efforts to improve the health of the population more broadly.<sup>4-6, 9, 10, 12, 13</sup>

While there has to date been little progress on widespread implementation of PCC and preconception health programmes and interventions, advocacy for preconception health initiatives is increasing internationally. Examples include a focus on the health of girls and women during the adolescent and reproductive years in the United Nations 2030 Agenda for Sustainable Development,<sup>14</sup> and in the Global Strategy for Women's, Children's and Adolescent's Health 2016-2030.<sup>15</sup> As a result, interventions that increase awareness of the importance of preconception health and that promote pregnancy planning and preparation are likely to be developed to meet the goals set out in these global strategies. National and local programmes and interventions are emerging<sup>10, 16, 17</sup> and already being tested and implemented in some countries such as the USA, China, Belgium and the Netherlands.<sup>18-20</sup> To inform and evaluate such initiatives and to track progress made towards optimising preconception health, there is a need for guidance on the assessment and monitoring of population-level indicators that measure the state of preconception health.

In the UK, the Preconception Partnership was established in 2018 as a multi-disciplinary advocacy coalition with the aim to improve preconception health. The Partnership has set out a conceptual framework for reporting and monitoring of preconception indicators in England based on a set of routinely collected datasets, or ‘core metrics’.<sup>21</sup> We define preconception indicators as medical, behavioural and social risk factors or exposures as well as wider determinants of health that may impact potential future pregnancies among all women and men of reproductive age.<sup>10, 17</sup> National data on these indicators would facilitate characterisation of the nation’s preconception health, monitoring of trends and identification of inequalities, to incite action from local and national governments and organisations to deliver resources for effective and appropriate interventions. Internationally, there is currently no comprehensive and recognised set of preconception indicators that could fulfil these functions using data sources available at a national level in countries such as England.

To inform the reporting of population-level preconception health in England, we aimed to conduct a review of relevant guideline and policy documents to identify a comprehensive set of indicators, and to map these against national data sources currently available. Moreover, we provide perspectives from (healthcare) professionals to illustrate how findings from population-level surveillance of preconception health may be used to inform the development of interventions and campaigns, and improve patient care in primary care and community settings.

## Methods

### Review of preconception guidelines, recommendations and policy reports

**Search strategy**—An electronic search was carried out in Google and Google Scholar in March 2021 by DS, and relevant guideline repositories and websites of professional organisations/associations and ministries of health were searched, to identify publicly available preconception guidelines, recommendations, position statements and policy reports in England and internationally. The following search terms were used: Preconception; Preconceptual; Pre-pregnancy; Before pregnancy; Pregnancy planning; Preparing for pregnancy AND Guidelines; Recommendations; Policy.

**Eligibility criteria**—Guidelines, statements and policy documents aimed at the public or patients, healthcare professionals and governments reporting on preconception indicators that could be assessed in individuals (i.e. not for example at health service or household level) were considered relevant. In addition, preconception recommendations published in English by other countries were included to identify additional preconception indicators reported internationally but not included in documents relevant to England. International documents were not included if no additional preconception indicators were identified beyond those already reported in documents relevant to England. Electronically available information considered relevant for identifying preconception indicators included documents and other online information sources from government organisations, national healthcare organisations, professional bodies and societies, and charitable organisations.

**Data extraction**—Key features of the guidelines, statements and policy documentation (including the overall topic, the target audience(s) and country), and all preconception indicators mentioned in these sources, were extracted by DS. The identified preconception indicators were grouped into overarching domains based on shared characteristics. Measures that describe the prevalence of the indicators were formulated based on the guidelines and recommendations reviewed.

### **Aligning preconception indicators with core data sources**

Following identification of preconception indicators, population-based national data sources from which prevalence data on indicators could be extracted were identified through known UK websites providing information on national datasets, national data reports, or surveillance of health indicators. Examples include websites from NHS Digital,<sup>22</sup> the UK Data Service,<sup>23</sup> Public Health Outcomes Framework,<sup>24</sup> and Office for National Statistics.<sup>25</sup> Eligible data sources included national routine datasets, national surveys, and national cohort studies. We excluded data sources if they did not include individual-level data for women and/or men of reproductive age (defined as aged 16-45 years<sup>3</sup>), or if data were not directly available or accessible through online data reports or tools. For each data source, information was summarised on the representativeness of the population, the method and frequency of data collection, reporting of relevant preconception indicators, and data access.

Preconception indicators were aligned with a data source where possible. If an indicator was not available but a comparable measure was reported in a data source, the comparable measure was included to reflect an approximation of the preconception indicator as specified in guideline and policy documents.

## **Results**

### **Preconception indicators**

The search for publicly available guidance on preconception health in England identified 15 clinical guidance or recommendation documents, three position statements, two policy reports, one e-Learning programme, and online information from one charitable organisation (Supplementary Table S1). Guidance was aimed at healthcare professionals, commissioners and providers, or the public; and was relevant to the general population of reproductive-aged women and men, individuals planning pregnancy, and/or populations with pre-existing medical conditions or at high risk of an adverse pregnancy or birth outcome. International guidance related to preconception health which reported additional indicators not described in documents relating to England included clinical preconception care recommendations from the USA and Canada, a position statement from Australia, and a policy brief from the World Health Organization (WHO) (Supplementary Table S1). Examples of international documents that were identified but that did not report preconception indicators not already reported in documents relevant to England included the Federation of Obstetric and Gynaecological Societies of India (FOGSI) Good Clinical Practice Recommendation on Preconception Care,<sup>26</sup> a call to action for preconception health promotion and care by the Ontario Public Health Association,<sup>27</sup> and a report commissioned by NHS Greater Glasgow and Clyde on Preconception health, education and care in Scotland.<sup>28</sup>

Preconception indicators were grouped into 12 domains containing a total of 66 indicators (Table 1). Detailed measures formulated based on guidelines and recommendations can be found in Supplementary Table S2. Several preconception indicators could be assessed using multiple measures, and separate measures were formulated for women and men, for high-risk groups, and categorical indicators (such as body mass index classifications) based on clinical guidance. While guidance was mainly focused on preconception health of women, some clinical guidelines,<sup>3, 4, 6, 12, 29, 30</sup> a Clinical Effectiveness Unit position statement<sup>12</sup> and Tommy's charity<sup>31</sup> reported on preconception indicators relevant to men.

### Core data sources

National data sources with relevant information on preconception health included 12 routine health datasets, five surveys, and two cohort studies (Table 2). Routine health datasets cover data reported in primary care, hospital, maternity, community and specialist health services, disease registries, and the census. National surveys are repeated cross-sectional surveys among a random representative sample, and national cohort studies include longitudinal population-based studies following the lives of people born in a specific week or year from birth onwards at 2-10 year intervals. Data for surveys and cohort studies are collected through questionnaires, face-to-face interviews, physical examinations, and biological samples. Anonymised annual data for individuals across their reproductive years are available to policymakers and researchers for the majority of data sources following protocol approval through NHS Digital, or the UK Data Service (Table 2). Key statistics from most routine datasets and surveys are published online at least annually. These reports do not cover all indicators measured in each data source, and are generally not aggregated specifically for women and men of reproductive age.

From the total number of 66 identified preconception indicators, 64 were reported in at least one data source (Table 1, Supplementary Table S1). Collectively, national routine datasets include data for all domains, and nearly all indicators except measures on adverse childhood experiences, preconception assessment and care, pregnancy intention, use of assisted reproductive technology (ART), dietary intake and physical activity. Data on indicators related to health behaviours including diet and physical activity are collected in detail and through validated methods in surveys and cohort studies. Measures of preconception health assessment and care and ART use were not identified in any current national data source.

### Discussion

This review is the first critical step in the process of developing a national surveillance system for preconception health in England. Based on national and international guidelines and policy documents, we identified a comprehensive set of preconception indicators that can be used to characterise and monitor the health, health behaviours and their wider determinants among women and men of reproductive age using available national population-based data sources. A national picture of preconception health can improve our understanding of the population's preconception needs, inform the development and evaluation of new campaigns and interventions, and thereby facilitate translation of evidence into actions to improve preconception health.

Existing public health surveillance systems in England, such as those managed by Public Health England<sup>32</sup> and the Office for National Statistics,<sup>25</sup> produce and publish regularly updated population-level data on a large number of indicators across a broad range of topics. These include wider determinants of health, and indicators relevant to preconception health such as obesity and smoking prevalence. We present an extension to these existing surveillance efforts based on indicators that are relevant to people of reproductive age, and that are recommended as indicators of optimal preconception health and care based on clinical guidance and policy reports. Our review identified a set of 66 preconception indicators across 12 domains covering wider determinants of health, and medical, behavioural, social and environmental risk factors. Measures that describe the prevalence of each indicator were formulated based on guidelines and recommendations reviewed, and are specific to women or men and high-risk groups where relevant.

Although not all indicators identified in our review are currently recorded in a data source representative of the English population of women and men of reproductive age, 64 of the 66 indicators are assessed and can already be described and monitored at a national level. Measures of preconception health assessment and care and ART use are not currently captured in any national data source, and pregnancy intention is not recorded in a routine dataset or annual survey. These measures should be considered for inclusion in routine datasets or annual surveys in the future to allow for comprehensive and timely monitoring and evaluation.

For the first time, we describe indicators relevant to men's preconception health, and indicators that can be measured at a national level rather than a local or state level. Indicators were aligned with a range of national data sources, including routine datasets, surveys and cohort studies. The majority of indicators were recorded in at least one routine health dataset commissioned by the National Health Service (NHS), which is a government-sponsored universal healthcare system and provider of the majority of care in England. The advantage of monitoring preconception indicators through a combination of these data sources from primary care, hospital, maternity, community and specialist health services is the wide population coverage with information on nearly all residents of England. National surveys and cohort studies complement routine data with indicators on health behaviours such as diet and physical activity comprehensively assessed among large nationally representative samples of the population.

Population-level surveillance indicators for preconception health and care have also been identified in the US by the National Preconception Health and Health Care (PCHHC) Initiative.<sup>33</sup> The indicator selection process by the PCHHC Initiative involved a consensus-based selection of 11 broad priority areas (domains), a review of state-based data systems, and identification of available measures relevant to each domain. Compared with the domains defined in our review, the PCHHC Initiative did not select environmental exposures, cervical screening, medication and genetic risk as priority areas, but identified self-rated general health status as an additional priority area, and separated the health behaviours domain into tobacco, alcohol and substance use, and nutrition and physical activity. A total of 96 measures were identified by the PCHHC Initiative, and these were reduced to 45 measures based on evaluation of each measure against predetermined criteria



(such as data quality and availability of comparable indicators across states), followed by a Delphi process among representatives from seven participating states to retain or exclude measures.<sup>33</sup> The 45 measures have more recently also been evaluated and condensed to ten preconception health indicators<sup>34</sup> and 30 preconception care indicators.<sup>35</sup> This comprehensive consensus building process may explain why the measures identified by the PCHHC Initiative were more restricted compared to our overall set of identified indicators. For example, the PCHHC Initiative indicators were relevant to women only, did not include medication use, immunisation, genetic factors and environmental exposures, and captured a limited number of measures to describe wider determinant of health and physical (chronic) health conditions. In line with our review, the PCHHC Initiative also identified preconception assessment and care (preconception counselling) and ART use as relevant indicators. These are not currently reported in national data sources in England, but are recorded in the Pregnancy Risk Assessment Monitoring System (PRAMS), which is a US state-based survey conducted between two and nine months postpartum among women with a live birth.<sup>33</sup>

There are some limitations and challenges to our review process and identified set of indicators. Firstly, this is a scoping review and academic/scientific databases were not searched. We aimed to identify indicators based on grey literature including guidelines, recommendations, policy reports, and other non-scientific documents from government organisations, national healthcare organisations, professional bodies and societies, and charitable organisations. These documents were of interest as they are intended for the public or patients, healthcare professionals and governments, who may directly act on recommendations. These recommendations may thereby result in changes in preconception health that can be measured as part of surveillance. While the comprehensive list of indicators may not be exhaustive, it provides a strong foundation for the development of a preconception health surveillance system in England. Moreover, as evidence and awareness on the benefits of improved preconception health and care continues to grow, it is likely that indicators and measures will expand and be refined over time. Our identified set of indicators will therefore need regular review and updating. Furthermore, the aim of this review was to inform surveillance of indicators that can be assessed at the individual-level, and indicators or measures at health service, practice, school, household or family-level were therefore beyond the scope of this review.

A number of indicators identified in our review are not relevant to all women of reproductive age, but are specific to women planning to become pregnant in the near future. Examples include taking a daily folic acid supplement, avoiding vitamin A (containing) supplements, and adjusting medication that is not recommended in pregnancy. National routine data sources in England do not currently assess pregnancy intention, although there are moves to include such a measure in the national maternity services dataset.<sup>21</sup> While the National Survey of Sexual Attitudes and Lifestyles (Natsal) includes a measure of pregnancy intention, this survey is only conducted every 10 years, and includes a limited number of other preconception indicators that could be described and monitored among women with planned pregnancies. Until routine data sources include a measure of pregnancy intention, a comprehensive set of preconception indicators cannot be described and monitored separately in women intending to become pregnant. Although data on contraceptive use may provide an

estimation of women ‘at risk’ of pregnancy, a better measure to assess pregnancy intention routinely is needed and research is underway to validate such a measure in the UK.<sup>36</sup> Meanwhile, GPs or other primary care professionals can simply ask women “...and are you thinking of having a(nother) baby in the next year or so?”, which can be incorporated as part of routine consultations to identify couples intending to become pregnant.<sup>37</sup> Since the majority of indicators are relevant to the health and wellbeing of all people of reproductive age, optimising risk factors may improve pregnancy and birth outcomes if an intended or unintended pregnancy occurs, as well as a woman’s health regardless of a future pregnancy.

In addition to the current lack of data on a few indicators, national datasets may be subject to data quality issues. Incomplete data is a common problem, and depending on the amount and reason of missing data this may result in biased prevalence estimates. Data quality is generally high in for example primary care and maternity datasets due to financial incentives to practices and service providers for achieving set targets. However, data from multiple sources may need to be combined to obtain more accurate estimates for some indicators, such as contraceptive use information from primary care, hospital and sexual and reproductive health services datasets. Assessment of indicators may change over time, for example as a result of changes in quality indicators for primary care, data structures and content requirements for health services, or survey questions. This may impact the accuracy of monitoring of changes in preconception health and care over time.

While acknowledging these potential limitations, surveillance of preconception indicators can be used to provide a snapshot of the health and health behaviours of women and men of reproductive age. When these indicators are stratified by wider determinants of health, they provide an understanding of needs and disparities in health and health care among subpopulations. Researchers may use the overview of indicators to identify outcomes to be targeted and assessed in intervention studies that aim to improve preconception health. Moreover, routine reporting on population-level indicators that benchmark the health of reproductive-aged people can be used to enhance accountability from governments and other relevant agencies for delivering interventions that remove barriers and support all women and men to improve their health.<sup>21</sup> The importance and utility of preconception health surveillance is further highlighted by the COVID-19 pandemic, when the prevalence of many indicators identified in this review is likely affected as a result of the stay-at-home advice and changes in access to health care services.<sup>38</sup> Investment in efficient routine data collection and monitoring of population, maternal and child health is recommended to determine the immediate and longer-term effects of COVID-19, and the additional needs of people of reproductive age.<sup>39, 40</sup>

The implications of preconception surveillance extend beyond research and policy advocacy, to directly and indirectly improve patient care, and inform the development and evaluation of education and awareness campaigns. Discussions with relevant stakeholders (Figure 1) revealed that, for example in primary care, surveillance data may indirectly influence patient care through the Quality Outcomes Framework (QOF).<sup>41</sup> This is a voluntary annual reward and financial incentive programme for general practitioner (GP) services in England, in which practices can score points based on achievements against a set of indicators. The QOF does not currently include preconception indicators, but high prevalence or increasing



trends may inform the inclusion of specific indicators, and thereby contribute to improved provision of preconception care among GPs.<sup>42</sup> Moreover, health visitors in England contribute to the provision of interconception care to mothers with infants and young children, and their partners. Prevalence and trend data on pre- and interconception indicators may inform risk assessments performed by health visitors, and indicate the need to develop resources to address issues that are (increasingly) common and may affect a next pregnancy. In addition to patient care, surveillance of preconception indicators may be used to inform campaign development and evaluation by identifying common indicators that could be targeted and would be relevant to a large proportion of the population. Prevalence rates of indicators may also be communicated to the target population for education purposes and to normalise sensitive topics such as mental health issues.

The identification of a comprehensive list of preconception indicators and determining their availability in national data sources are a first step towards national surveillance of preconception health in England. Analyses of routine health datasets are currently underway to obtain national prevalence estimates of preconception indicators. Further planned work includes linkage of these datasets to allow analyses of associations between preconception indicators and maternal and child health outcomes to provide evidence on the potential impact of improved preconception health. Our findings on the prevalence of indicators and strength of associations with relevant outcomes – together with considerations of data quality, modifiability, and input from stakeholder and public consultations – will inform the prioritisation of a reduced set of key indicators for ongoing surveillance of preconception health in England. A dashboard bringing indicators from multiple sources together through an interactive online platform will make findings readily available to health care providers, policy makers, the public, and relevant stakeholders. Informed by the list of preconception indicators presented in this review and by the PCHHC Initiative, we recommend other countries follow a similar process to develop a surveillance system for preconception health based on available regional or national datasets.

## Conclusion

Several national and international guideline and policy documents emphasise the need to optimise preconception health to prevent adverse outcomes in the next generation, and improve the overall health and wellbeing of women and men of reproductive age irrespective of any pregnancies they may have. Nearly all preconception indicators identified from these documents can be described and monitored using national data sources in England. Measures of preconception health assessment and care, pregnancy intention and ART use are not currently annually recorded in any national data source, and should be considered for inclusion in routine datasets or annual surveys in the future. Monitoring of a comprehensive set of preconception indicators may contribute to informing patient care, developing and evaluating public awareness campaigns, and strengthening advocacy efforts for government resources and action. This work informs the next steps towards developing a national surveillance system, to improve preconception health in England.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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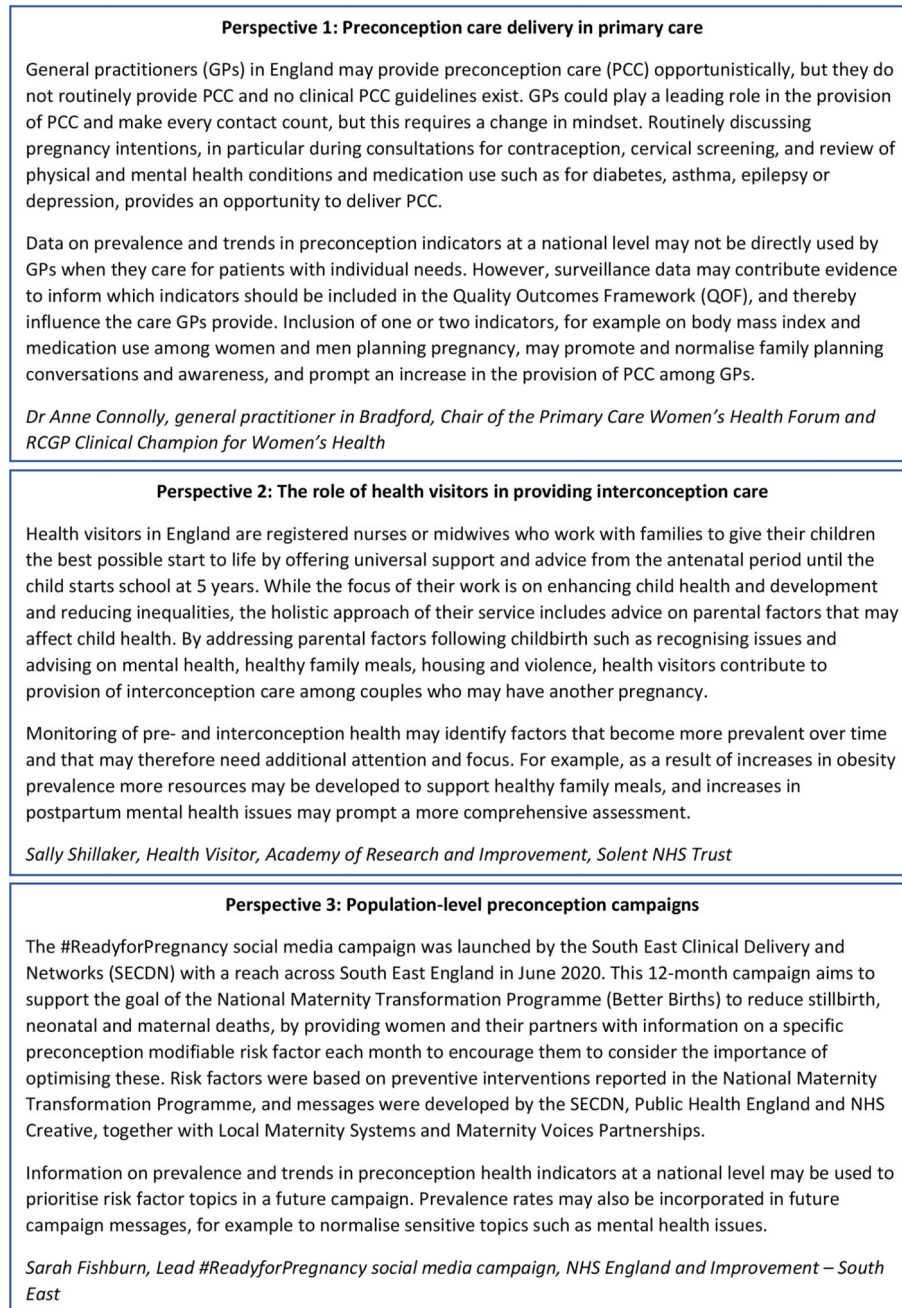
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**Figure 1. Professional perspectives illustrating the value of population-level surveillance of preconception indicators.**



**Table 1**  
**Summary overview of identified preconception indicators and their recording in national data sources**

Domain	Indicator	Indicator source (reference)				Possible data source			
		Clinical guidance	Policy report	Position statement	Charitable organisation	E-Learning	National routine dataset	National survey	National cohort study
Wider determinants of health	Ethnicity		10				RCGP, CPRD, MSDS, HES, ONS, NDA	HSE, NDNS, ONS, ALAS,	MCS, BCS70
	Education		10				HES, ONS	HSE, ONS, ALAS,	MCS, BCS70
	Employment		10				RCGP, CPRD, MSDS, HES, ONS	HSE, ONS, ALAS, ONS	MCS, BCS70
	Financial security		10				ONS	ONS	
	Housing		10				ONS	ONS	BCS70
	Deprivation		10				RCGP, CPRD, MSDS, HES, ONS	NDNS, ONS	MCS, BCS70
	Complex social factors		10				MSDS		
	Adverse childhood experiences		10					ONS	
	Migrant health factors		10				RCGP, CPRD	ONS	
	Preconception assessment and care			3, 6, 43, 44					
Health care	Routine general practitioner (GP) check-up			3			RCGP, CPRD		
	Routine dental appointment			7		45	NHSDS		
	Domestic abuse (physical and emotional)		10	5	31	45	RCGP, CPRD	ONS	MCS, BCS70
Emotional and social health and support	Support network / social support		10		31		MSDS		
	Pregnancy intention			3, 4, 30	31			Natal	
Reproductive health and family planning	Maternal age		10	3, 30			RCGP, CPRD, MSDS, HES		MCS, BCS70
	Paternal age			29			Birth registrations		
	Interpregnancy interval			3			RCGP, CPRD, MSDS, HES		

Domain	Indicator	Indicator source (reference)				Possible data source			
		Clinical guidance	Policy report	Position statement	Charitable organisation	E-Learning	National routine dataset	National survey	National cohort study
	Obstetric history	3, 4, 7, 8, 43, 44	10		31		RCGP, CPRD, HES, MSDS, NCARDS	Natsal	MCS, BCS70
	Previous breastfeeding experiences					45	CSDS		BCS70
	Fertility problems	3, 30				45	RCGP, CPRD		
	Contraception	3, 4, 43, 46, 47	10	12	31	45	RCGP, CPRD, SRHAD	HSE	MCS
	Assisted reproductive technology	3, 30		12					
Health behaviours	Folic acid supplementation	3-5, 30, 43	10	12	31	45	MSDS, NDA		
	Other vitamin supplementation	4, 5		11	31	45		NDNS	
	Vitamin deficiency	4, 5, 7	9	13	31		RCGP, CPRD	NDNS	
	Dietary intake	3-5, 30, 48, 49	10	12	31	45		NDSD	BCS70
	Physical activity	4, 49	10		31	45		ALAS	
Weight	3-5, 30, 49	10	12	31	45	RCGP, CPRD		Natsal, HSE, ONS, NDNS, ALAS,	MCS, BCS70
	Eating disorder	46			31		RCGP, CPRD		
	Tobacco use	3-5, 30	10	12	31	45	RCGP, CPRD	Natsal, HSE, ONS	MCS, BCS70
	Second-hand smoke exposure	4, 30			31			HSE	
	Alcohol consumption	3-5, 30	10	12	31	45	RCGP, CPRD	Natsal, HSE, ONS	MCS, BCS70
	Substance use	3-5, 30	10	12	31	45	RCGP, CPRD	Natsal	MCS
Environmental exposures	Toxic or hazardous substances or exposures	3, 30, 50					RCGP, CPRD, MSDS, HES, ONS	ONS, NDNS	MCS, BCS70
Cervical screening	Cervical screening	3, 30	10	12	31	45	RCGP, CPRD		
Immunisation and infections	Immunisation	3, 4, 8, 30	10	12	31	45	RCGP, CPRD		
	Sexually transmitted diseases	3, 30	10	12	31	45	RCGP, CPRD	Natsal	
Mental health conditions	Mental health problem	3-5, 29	10	12	31	45	RCGP, CPRD, HES, ONS	Natsal, HSE, ONS	MCS, BCS70
	Previous antenatal or postnatal mental illness	7				45	RCGP, CPRD, CSDS		

Domain	Indicator	Indicator source (reference)				Possible data source			
		Clinical guidance	Policy report	Position statement	Charitable organisation	E-Learning	National routine dataset	National survey	National cohort study
	Severe mental health conditions	3					RCGP, CPRD, HES		
Physical health conditions	Epilepsy	3, 4			31	45	RCGP, CPRD, HES	Natsal	BCS70
	Diabetes mellitus	3, 4, 29, 43		12	31	45	RCGP, CPRD, HES, NDA	Natsal, HSE	BCS70
	Polycystic ovary syndrome				31		RCGP, CPRD, HES	Natsal	
	Endometriosis	30, 51			31		RCGP, CPRD, HES	Natsal	
	Thyroid disease	3, 30					RCGP, CPRD, HES	Natsal	
	Chronic hypertension	3, 4		12		45	RCGP, CPRD, HES	Natsal, HSE	BCS70
	Cardiovascular disease	3, 4, 47					RCGP, CPRD, HES	Natsal	
	Previous thromboembolism	3					RCGP, CPRD, HES		
	Renal disease	3					RCGP, CPRD, HES		
	Asthma	3, 4			31		RCGP, CPRD, HES		BCS70
	Rheumatological conditions	3				45	RCGP, CPRD, HES		
	Inflammatory bowel disease	3, 52					RCGP, CPRD, HES		
	Sickle-cell disease or thalassaemia	3, 4		12			RCGP, CPRD, HES, NCARDRS		
	Hepatitis B	3, 30					RCGP, CPRD		
	Lupus	8					RCGP, CPRD, HES		
	Phenyketonuria (PKU)	6					RCGP, CPRD, HES, NCARDRS		
Developmental disability	8					RCGP, CPRD, HES, NCARDRS			
Cancer	30					RCGP, CPRD, HES, NCARDRS, NCSRAS		BCS70	
Female genital mutilation	3, 30					RCGP, CPRD, MSDS, HES			
Pelvic floor dysfunction	53					RCGP, CPRD, HES			
Medication	Overall use	3, 30			31		RCGP, CPRD, HES	HSE	
	Not recommended when planning pregnancy	3-5		12			RCGP, CPRD, HES		
Genetic risk	Personal or family history of a generic disorder	3, 4, 30	10	12	31		RCGP, CPRD, NCARDRS		

Domain	Indicator	Indicator source (reference)				Possible data source			
		Clinical guidance	Policy report	Position statement	Charitable organisation	E-Learning	National routine dataset	National survey	National cohort study
	Previous pregnancy affected by an inherited genetic disorder	3							
	Family history of diabetes	29, 43							RCGP, CPRD, NCARDRS RCGP, CPRD

Abbreviations: ALAS, Active Lives Adult Survey; BCS70, 1970 British Cohort Study; CPRD, Clinical Practice Research Datalink; CSDS, Community Services Dataset; HES, Hospital Episode Statistics; HSE, Health Survey for England; MCS, Millennium Cohort Study; MSDS, Maternity Services Dataset; Natsal, British National Survey of Sexual Attitudes and Lifestyles; NCARDRS, National Congenital Anomaly and Rare Disease Registration Service; NCSRAS, National Cancer Registration and Analysis Service; NDA, National Diabetes Audit; NDNS, National Diet and Nutrition Survey; NHSDS, NHS Dental Statistics; ONS, Office for National Statistics; RCGP, Royal College of General Practitioners Research and Surveillance Centre database; SRHAD, Sexual and Reproductive Health Activity Dataset.

**Table 2**  
**Core data sources for the reporting and monitoring of preconception indicators in England**

Data source	Description	Data access	More information
<i>National routine datasets</i>			
Royal College of General Practitioners (RCGP) Research and Surveillance Centre (RSC) database	The RCGP RSC is a network of primary care practices, which extracts data from the computerised medical record systems of over 1,700 practices in England. Up to early 2020, data covered approximately 5% of the population in England, <sup>54</sup> which has increased substantially as the RCGP RSC expands. Includes individual-level annual data of women and men aged 16-45 who are registered with a general practitioner (GP) practice participating in the RCGP RSC network on wider determinants of health, health care, reproductive health and family planning, health behaviours, cervical screening, infections, mental and physical health conditions, medication, and genetic risk.	Researchers may access anonymised individual-level data following protocol approval.	<a href="https://www.rcgp.org.uk/clinical-and-research/our-programmes/research-and-surveillance-centre.aspx">https://www.rcgp.org.uk/clinical-and-research/our-programmes/research-and-surveillance-centre.aspx</a> [accessed 22/03/2021]
Clinical Practice Research Datalink (CPRD)	Research service by the Department of Health and Social Care. Collects data from the computerised medical record systems of a network of GP practices in the UK. Data cover approximately 7% of the UK population. <sup>55</sup> Includes individual level annual data of women and men aged 16-45 who are registered with a GP practice participating in the CPRD network on wider determinants of health, health care, reproductive health and family planning, health behaviours, cervical screening, infections, mental and physical health conditions, medication, and genetic risk.	Researchers may access anonymised individual-level data following protocol approval.	<a href="https://www.cprd.com/">https://www.cprd.com/</a> [accessed 22/03/2021]
Maternity Services Dataset (MSDS)	Mandatory data collection by the National Health Service (NHS) for all providers of NHS Maternity Services in England. Data are collected from the point of the first booking appointment until mother and baby(s) are discharged from maternity services. Includes individual-level annual data of pregnant women aged 16-45 years on wider determinants of health, emotional and social health and support, reproductive health and family planning, health behaviours, infections, mental and physical health conditions, and genetic risk.	Access to anonymised individual level data is available to researchers following protocol approval through the NHS Digital Data Access Request Service, and key statistics are published online at least annually	<a href="https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-sets/maternity-services-data-set">https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-sets/maternity-services-data-set</a> [accessed 22/03/2021]
Birth registrations	Birth statistics are derived from information recorded when live births and stillbirths are registered as part of civil registration, which is a legal requirement. Registration of births is a service carried out by the Local Registration Service in partnership with the General Register Office. Birth statistics for England and Wales are produced by the Office for National Statistics. Birth statistics include individual-level annual data on the child and both parents, including the country of birth and age of the mother and father (or second parent).	Data are held by the Office for National Statistics, and key statistics are published online annually.	<a href="https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/datasets/birthsbyparentscharacteristics">https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/datasets/birthsbyparentscharacteristics</a> [accessed 22/03/2021]
Hospital Episode Statistics (HES)	Data collection by the NHS containing details of all admissions, outpatient appointments and accident and emergency attendances at NHS hospitals in England. Includes individual-level annual data of women and men aged 16-45 on wider determinants of health, mental and physical health conditions, reproductive health, and medication.	Access to anonymised individual level data is available to researchers following protocol approval through the NHS Digital Data Access Request Service, and key statistics are published online at least annually.	<a href="https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/hospital-episode-statistics">https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/hospital-episode-statistics</a> [accessed 22/03/2021]
Community Services Dataset (CSDS)	Mandatory collection of data by the NHS for all providers of publicly funded community health trusts, and local authorities. Includes individual-level annual data of women aged 16-45 with a previous live birth on postpartum depression.	Access to anonymised individual level data is available to researchers following protocol approval through the NHS Digital Data Access Request Service, and key statistics are published online at least annually.	<a href="https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-sets/community-services-data-set">https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-sets/community-services-data-set</a> [accessed 22/03/2021]

Data source	Description	Data access	More information
NHS Dental Statistics (NHSDS)	Collection of data by the NHS for all NHS dentists. Includes individual-level annual data of women and men aged 16–45 using NHS Dental Services.	Researchers may contact NHS Digital to discuss access to anonymised individual-level data, and key statistics are published online annually.	<a href="https://digital.nhs.uk/data-and-information/publications/statistical/nhs-dental-statistics">https://digital.nhs.uk/data-and-information/publications/statistical/nhs-dental-statistics</a> [accessed 22/03/2021]
National Diabetes Audit (NDA)	Mandatory collection of data by the NHS for all GP practices and specialist services such as diabetes clinics, linked with HES data. Includes individual-level annual data of women and men aged 16–45 on wider determinants of health and diabetes (including pre-existing diabetes in pregnancy).	Researchers may contact NHS Digital to discuss access to anonymised individual-level data, and key statistics are published online at least annually.	<a href="https://digital.nhs.uk/data-and-information/clinical-audits-and-registries/national-diabetes-audit">https://digital.nhs.uk/data-and-information/clinical-audits-and-registries/national-diabetes-audit</a> [accessed 22/03/2021]
National Cancer Registration and Analysis Service (NCRAS)	Data collection services by Public Health England on all cases of cancer diagnosed and treated in the NHS in England based on multiple data sources including records from hospitals, general practices, pathology laboratories and community prescribing services. Includes individual-level annual data of women and men aged 16–45 with (prior) cancer (treatment).	Access to anonymised individual level data is available to researchers following protocol approval through the Public Health England Office for Data Release (ODR), and key statistics are published online annually.	<a href="https://www.cancerdata.nhs.uk">https://www.cancerdata.nhs.uk</a> [accessed 22/03/2021]
National Congenital Anomaly and Rare Disease Registration Service (NCARDRS)	Data collection services by Public Health England collecting data on over 1,000 different congenital anomalies and rare diseases, such as congenital anomalies, developmental disability, perinatal and infant mortality. Includes individual level annual data of women and men aged 16–45 with congenital anomalies and rare diseases.	Access to anonymised individual level data is available to researchers following protocol approval through the Public Health England Office for Data Release (ODR), and key statistics are published online annually.	<a href="https://www.gov.uk/guidance/the-national-congenital-anomaly-and-rare-disease-registration-service-ncardrs">https://www.gov.uk/guidance/the-national-congenital-anomaly-and-rare-disease-registration-service-ncardrs</a> [accessed 22/03/2021]
Sexual and Reproductive Health Activity Dataset (SRHAD)	Data on contraception are collected on behalf of Public Health England. Data collection is mandatory for all providers of NHS Sexual and Reproductive Health services. Includes individual level annual data of women and men aged 16–45 who use Sexual and Reproductive Health services for contraceptive reasons on uptake of long acting reversible contraceptives, contraceptive pill, and emergency contraception	Researchers may contact NHS Digital to discuss access to anonymised individual-level data, and key statistics are published online annually.	<a href="https://digital.nhs.uk/data-and-information/data-collections/sexual-and-reproductive-health-activity-data-set-srhad-collection">https://digital.nhs.uk/data-and-information/data-collections/sexual-and-reproductive-health-activity-data-set-srhad-collection</a> [accessed 22/03/2021]
Census	The census is a survey conducted every 10 years by the Office for National Statistics (ONS). Data are collected from every household in England and Wales. Includes individual-level data of women and men aged 16–45 on wider determinants of health, and mental and physical health.	Researchers can access the majority of data through the UK Data Service, and key statistics are published online.	<a href="https://www.ons.gov.uk/census">https://www.ons.gov.uk/census</a> [accessed 22/03/2021]
<b>National surveys</b>			
Office for National Statistics (ONS) Schoenaker et al	The ONS is an independent organisation who collect, analyse and disseminate statistics related to the economy, society and population in the UK. In addition to the census, data are collected through regular and repeated individual and household surveys, face-to-face interviews and telephone interviews (such as the Annual Population Survey and the Crime Survey for England and Wales) which may be combined with data from organisations (such as the Department for Education and policy recorded crime data). Surveys are designed to be representative of people or households living in England and Wales. Includes individual-level annual data of women and men aged 16–45 on wider determinants of health, emotional and social health and support, tobacco use, and mental and physical health. Data on alcohol use are collected but not annually.	Researchers can access the majority of data through the UK Data Service, or data may be available to accredited or approved researchers for specific research projects, and key statistics are published online at least annually.	<a href="https://www.ons.gov.uk/">https://www.ons.gov.uk/</a> [accessed 22/03/2021]
British National Survey of Sexual Attitudes and Lifestyles (Natsal)	Repeated cross-sectional surveys carried out by a multi disciplinary team of researchers from University College London, the London School of Hygiene & Tropical Medicine, the University of Glasgow and NatCen Social Research. Individual-level data are collected every 10 years from a random sample of 10,000 adults aged 16–74 living in private households in the UK, and an additional sample of 5,000 adults aged 16–34 for more	Researchers can contact the Natsal study team about collaboration on analysis of Natsal data, which is available through the UK Data Archive. Reference tables with key	<a href="https://www.natsal.ac.uk/">https://www.natsal.ac.uk/</a> [accessed 22/03/2021]



Data source	Description	Data access	More information
Health Survey for England (HSE)	detailed exploration of sexual health and behaviours in this age-group. Data are collected through face-to-face interviews, and self-completion questionnaires. Includes individual-level data of women and men aged 16-45 on reproductive health and family planning, health behaviours, immunisation and infections, mental health conditions, and physical health conditions.	statistics are published online for each survey.	
Health Survey for England (HSE)	Repeated cross-sectional surveys commissioned by NHS Digital and carried out by NatCen Social Research and University College London to monitor the nation's health and health related behaviours. Individual-level data are collected from a random sample of adults aged 16 and over residing at private residential addresses. Data are collected through face-to-face interviews, self-completed questionnaires and a follow-up nurse visit to collect anthropometric measurements and blood samples. Each year, approximately 8,000 adults complete the survey. Includes individual-level annual data of women and men aged 16-45 on wider determinants of health, health behaviours, mental and physical health conditions, and medication. Data on contraception and physical activity are collected but not annually.	Researchers can access the majority of data through the UK Data Service, and key statistics are published online annually.	<a href="https://digital.nhs.uk/data-and-information/publications/statistical/health-survey-for-england">https://digital.nhs.uk/data-and-information/publications/statistical/health-survey-for-england</a> [accessed 22/03/2021]
National Diet and Nutrition Survey (NDNS)	Repeated cross-sectional surveys carried out on behalf of Public Health England and the UK Food Standards Agency collecting detailed individual-level information on the food consumption, nutrient intake and nutritional status of the general population living in private households in the UK. Data are collected through an interview, a 4-day estimated diet diary, physical measurements and a blood and urine sample. Each year, data are collected from 500 adults. Includes individual-level annual data of women and men aged 16-45 on wider determinants of health, nutrition, and weight.	Researchers can access the majority of data through the UK Data Service, and results and time trends are published online approximately every two years.	<a href="https://www.gov.uk/government/collections/national-diet-and-nutrition-survey">https://www.gov.uk/government/collections/national-diet-and-nutrition-survey</a> [accessed 22/03/2021]
Active Lives Adult Survey (ALAS)	Repeated cross-sectional surveys carried out on behalf of government agencies including Sport England, Arts Council England and Public Health England by Ipsos MORI collecting individual-level data on how adults engage with sport and physical activity. The survey is sent out to a random sample of households across England selected from the Royal Mail's Postal Address File which has a very high coverage of private residential addresses. Each year, approximately 175,000 people complete the survey. Data are weighted to Office for National Statistics population measures for geography and key demographics. Includes individual-level annual data of women and men aged 16-45 on wider determinants of health, nutrition, physical activity and weight.	Researchers can access the majority of data through the UK Data Service. Key statistics are published online annually.	<a href="https://www.sportengland.org/know-your-audience/data/active-lives">https://www.sportengland.org/know-your-audience/data/active-lives</a> [accessed 22/03/2021]
<b>National surveys</b>			
Millennium Cohort Study (MCS)	Longitudinal population-based cohort study following the lives of 19,517 children born across England, Scotland, Wales and Northern Ireland in 2000-01. Since the initial birth survey, the cohort has been followed up at ages 3, 5, 7, 11, 14 and 17 years. Data are collected using questionnaires and interviewer-administered physical measurements. Includes individual-level cross-sectional data (longitudinal when additional follow-up surveys are completed in the future) of women and men aged 17 on wider determinants of health, emotional and social health and support, reproductive health and family planning, health behaviours, and physical and mental health conditions.	Researchers can access the majority of data through the UK Data Service.	<a href="https://cls.ucl.ac.uk/cls-studies/millennium-cohort-study/">https://cls.ucl.ac.uk/cls-studies/millennium-cohort-study/</a> [accessed 22/03/2021]
1970 British Cohort Study (BCS70)	Longitudinal population-based cohort study following the lives of more than 17,000 people born in England, Scotland and Wales in a single week of 1970. Since the initial birth survey, the cohort has been followed up at ages 5, 10, 16, 26, 30, 34, 38, 42 and 46. Data are collected using questionnaires, interviews and assessments. Includes individual-level data of women and men aged 16-42 on wider determinants of health, emotional and social health and support, reproductive health and family planning, health behaviours, and physical and mental health conditions.	Researchers can access the majority of data through the UK Data Service.	<a href="https://cls.ucl.ac.uk/cls-studies/1970-british-cohort-study/">https://cls.ucl.ac.uk/cls-studies/1970-british-cohort-study/</a> [accessed 22/03/2021]

Abbreviations: GP, general practitioner; NHS, National Health Service.

Data sources that were identified, but not considered relevant include the General Practice Quality Outcomes Framework (includes practice-level but not individual-patient level data on relevant preconception indicators), the Mental Health Services Data Set (includes data on care provided to people using mental health services, but no individual-level data on diagnosis of mental health conditions), and the Inflammatory Bowel Disease Registry (IBDR) (no individual-patient level data available for research or accessible online).