BMJ Open Fetal alcohol spectrum disorder resources for health professionals: a scoping review protocol

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ABSTRACT

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Dr Josephine Chidinma Okurame; josephine.agu@sydney.edu.au **Introduction** People with fetal alcohol spectrum disorder (FASD) encounter a range of health and allied health providers and require specialised support to ensure health services are provided safely and effectively. Not all health professionals possess the knowledge or expertise required for the identification, assessment, referral and management of FASD. Accessible resources for understanding and managing FASD can help create awareness in health professionals and ensure patients receive the correct diagnosis and timely access to the necessary supports and services. The aim of this scoping review is to identify and analyse FASD resources for health professionals.

Methods and analysis A comprehensive search of eight databases (MEDLINE, Scopus, PsycINFO, CINAHL, PubMED, EMBASE, Web of Science and Trip Medical Database) and nine grey literature databases (FASD Hub, NOFASD Australia, National Organisation for FASD, FASD United, HealthInfoNet, Proof Alliance, Child Family Community Australia, Foundation for Alcohol Research & Education and the Australian Department of Health websites) will be conducted using three search engines including PubMed, Ovid and Google advanced search (search dates: October 2021 to May 2022). Consultations will also be carried out with international and national experts in the diagnosis/ management of FASD to obtain any additional relevant published or unpublished resources. Inclusion criteria were developed to guide the selection of resources that are publicly available, primarily focused on FASD and curated for health professionals for the identification, management or referral of FASD. Critical appraisal process will be executed using the Appraisal of Guidelines for REsearch & Evaluation II (AGREE II) tool to assess the quality of selected resources.

Ethics and dissemination Ethical approval is not required for the scoping review. Scoping review results will be presented at relevant national and international conferences and published in peer-reviewed journals. Search results will be made available to ensure reproducibility and transparency.

INTRODUCTION

Fetal alcohol spectrum disorder (FASD) is one of the leading causes of developmental disabilities that are non-genetic in nature, with a global prevalence of approximately

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This scoping review will be the first of its kind to examine fetal alcohol spectrum disorder (FASD) resources for health professionals to aid with appropriate management.
- ⇒ The review will follow an established methodological framework for conducting scoping reviews in the JBI Manual for Evidence Synthesis and use the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews checklist to improve the reporting of scoping reviews.
- ⇒ Our review will highlight the resources that are deemed high quality from the critical appraisal and recommendations on their use and access will be provided.
- ⇒ The primary focus on FASD resources may limit the inclusion of resources for other overlapping neuro-developmental disorders.
- ⇒ The strength and relevance of this scoping review is limited by the quality of the resources identified.

 $0.81.^{1}$ A closer observation using conservative analytical approaches reveal higher crude prevalence rates in Western countries like the USA (1.1%-5%),² UK $(1.8\%)^{3}$ and Canada (1.8%).⁴ These prevalence statistics highlight the importance of allocating more attention and resources to FASD screening and diagnostic services as well as health promotion initiatives to advance the awareness and prevention of maternal alcohol consumption.

FASD is a form of acquired brain injury which occurs in utero and manifests as a neurodevelopmental disorder and as a term, it collectively describes a range of prenatal alcohol exposure-related symptoms including stunted growth, physical and behavioural abnormalities, birth defects, craniofacial anomalies and neurodevelopmental impairments.^{5–7} FASD is often referred to as an invisible disability as only 10% of people have the facial features,⁸ with most scoring in the low-average range of intellectual ability.

Table 1	Stages of the scoping review process	
Stage number	Process	
Stage 1	Define the research question and objectives	
Stage 2	Develop the inclusion criteria in alignment with the research question(s) and objective(s)	
Stage 3	Planned approach to evidence searching (search strategy)	
Stage 4	Search the evidence (evidence screening)	
Stage 5	Evidence selection	
Stage 6	Evidence extraction	
Stage 7	Evidence analysis	
Stage 8	Evidence reporting and presentation	
Stage 9	Evidence summary in relation to review purpose, making conclusions and highlighting implications of findings. Each stage of the current methodological framework is discussed in further detail	

Individuals with FASD experience learning and academic challenges, behavioural issues, attention deficit hyperactivity disorder, problems with physical health, mental health, speech, motor skills, hearing and vision impairments. As a result, people with FASD encounter a range of health and allied health providers and require specialised support to ensure health services are provided safe and effectively.

Health professionals play a significant role in the prevention of alcohol exposure in pregnancy and development of FASD by providing interventions and education to pregnant women. In Australia, the majority of women want health professionals to ask pregnant women about alcohol use during pregnancy and advise them about the possible effects.⁹ However, health professionals have voiced their hesitance to have discussions around alcohol consumption with pregnant women mainly due to a lack of confidence and insignificant resources available to provide follow-up services or address alcohol-related issues.^{10–12} We believe there are limited resources¹³

available to educate health professionals on how to work with people with FASD and most health professionals possess limited expertise or knowledge base for the identification, assessment, referral and management of FASD in the absence of consistent and standardised screening tools.¹⁴ To ensure the appropriate management and referral of such patients, health professionals need to be equipped with efficient tools.

We will conduct a scoping review to identify and evaluate resources currently available to health professionals about the recognition, diagnosis and management of FASD. The working definition of the term 'resources' in this review refers to the successive itemisation of instructions in the form of frameworks, guides, tools, instruments, applications or models that are developed for health professionals in the management and prevention of FASD.

METHODS

Protocol design

This scoping review utilises a version of Arksey and O'Malley's¹⁵ methodological framework for conducting scoping reviews,¹⁵ which has been further developed by Levac and colleagues in 2010¹⁶ and the Joanna Briggs Institute (JBI) in 2014¹⁷ and 2020,¹⁸ emphasising on the importance of conducting trustworthy, rigorous and transparent scoping reviews.

This scoping review will be reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRIS-MA-ScR) and the latest JBI guidance for authors of scoping reviews will be used to organise the review process¹⁵ into nine stages (table 1).

Stage 1: define the research questions and objectives

The primary research question of this scoping review is as pertains to diagnosis, assessment, referral and/or management of FASD, what resources or guidelines are

Table 2 Inclusion criteria for resources		
Availability	Resource must be publicly available and searchable online, with an ISBN or PMID number, or in printed format	
Topic or focus	Primary focus of content should be FASD	
Target group	Resource should target healthcare professionals including medical practitioners, allied healthcare practitioners and nurses	
Aim/objective	Resource should aim to aid in the identification, management, and referral of FASD	
Language	Resource should be published in English	
Time frame	None. All resources can be included provided the terminologies and classifications of FASD and ELT (Early Life Trauma) from older resources are not outdated	
Resource development location	Resources may be developed both internationally or nationally that is, within Australia	

FASD, fetal alcohol spectrum disorder.

Table 3 Information sources for search or consultation		
		Date of engagement
Databases	MEDLINE, Scopus, PsycINFO, CINAHL, PubMED, EMBASE, Web of Science and Trip Medical Database	Initial Search: October to November 2021 Updated Search: March to April 2022
Grey literature	 FASD Hub, NOFASD Australia, National Organisation for FASD (UK), FASD United (previously known as The National Organization for Fetal Alcohol Syndrome) (USA), HealthInfoNet, Proof Alliance, Child Family Community Australia (CFCA), Foundation for Alcohol Research & Education (FARE), Australian Department of Health websites ► Australian Department of Health: National ACT NSW NT QLD TAS VIC WA 	November 2021 to February 2022
Consultation	Experts in diagnosis/management of FASD. Including paediatricians and allied health professionals working in FASD assessment clinics and child development units	Estimated for November 2022
Search engines	PubMed, OVID and Google advanced search*	-

*As per other review protocols,^{5 25} the first 100 results from the Google advanced search will be screened to determine eligibility for inclusion. FASD, fetal alcohol spectrum disorder.

available for health professionals? Secondary research questions include:

- 1. What is the primary purpose of each resource/guideline for example, screening, diagnosis, behavioural management or referral and can they be implemented?
- 2. What is the quality of these resources as assessed using a validated critical appraisal tool?

Stage 2: develop the inclusion criteria

The eligibility criteria for this scoping review allow capture of a wide range of existing literature, including but not limited to meta-analyses or systematic reviews, primary research studies, books, policies, guidelines, programmes, professional development and information-based resources for example, factsheets, podcasts, apps, videos and websites. Hereafter all sources of information will be referred to as resources. There are no limits on the time frame of publications, but resources must be in English and targeting health professionals. All resources must address FASD and should be usable by all health and allied health professionals. Inclusion criteria are outlined in table 2.

Stage 3: planned approach to evidence searching (search strategy) The evidence search will be conducted by sourcing resources from both peer-reviewed and grey literature (published or unpublished) using search engines including OVID (for Medline) and Google advanced

Table 4 Search category, terms and synonyms			
Search category	Search terms and synonyms		
FASD	'Fetal alcohol spectrum disorder' OR 'Fetal alcohol syndrome' OR 'Fetal alcohol exposure' OR 'Prenatal alcohol exposure' FASD OR FAS OR 'Alcohol related neurodevelopmental disorder' OR ARND OR 'Alcohol related birth defects'		
'Resources	'Factsheets' OR 'Policy' OR 'Guidelines' OR 'Information Sheet' OR 'Referral' OR 'Management' OR 'Identification' OR 'Assessment' OR 'Video' OR 'Podcasts' OR 'Media' OR 'Webcast' OR 'professional development' ? textbook/book, ? video ? online resources ? Guide		
Target population	'Health professionals' OR 'Health practitioners' OR 'healthcare professionals' OR 'Allied health practitioners' OR 'Allied health professionals' OR 'Nurses' OR 'Medical Practitioners' OR 'Doctor' OR 'Physicians' OR 'Health personnel' OR Psychologists		

*Different spellings for some words will be taken into consideration during the search for example, 'fetal versus 'foetal'. FASD, fetal alcohol spectrum disorder.



Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram for the scoping review process.

Table 5 Draft data extraction/charting table for health professionals' FASD resources		
Category	Details	
Author(s)	Resource developers	
Year of publication		
Country of origin	Source country of origin	
Resource source	Eg, Peer-reviewed articles, HealthInfoNet, FASD portal, Health promotion resources, expert recommendations, grey literature, Google search engines, etc.	
Study population	Target sample details-type of health professional for example, medical practitioners, allied healthcare practitioners, nurses and others	
Resource purpose/category	Primary objective or aim of the resource to be categorised into either (1) Identification, (2) Management or (3) Referral of FASD or any combination of the 3	
Type of resource	Guidelines, worksheets, policy documents, information-based resources, screening and/or assessment tools	
Resource outcome measure	Measurement variables	
Resource delivery method	Online, paper/ print material, interview-style, audio-visual, resource packages, social media campaigns, training course, etc	
Resource evaluation	Impact evaluation, effectiveness, reported outcomes, validation	
Evidence-base of the resource	Published findings, formal evaluation, evidence that informed resource development	
Resource information	Resource reference, weblink, any costs associated with the resource for example, free online download or paid purchase with cost details specified. Resource versions (English only or transcribed in other languages)	
Other relevant information		
FASD, fetal alcohol spectrum disorder.		

Table 6	Ie 6 The AGREE II quality appraisal tool (summarised from the original AGREE II document) ²¹				
Domain	Domain title	Item description (Total 23)			
Domain 1	SCOPE AND PURPOSE	3 Items			
	Covers the overall aims of the resource, specific heath questions and target populations	1. Overall objective(s) of the resource is (are) specifically described			
		2. Health question(s) covered by the resource is (are) specifically described			
		3. The population (patients, public, etc) to whom the resource is meant to apply is specifically described			
Domain 2	STAKEHOLDER INVOLVEMENT	3 Items			
	Focuses on the extent to which	4. The resource development group includes individuals from all relevant professional groups			
	the resource was developed by the appropriate stakeholders	5. The views and preferences of the target population (patients, public, etc.) have been sought			
	and represents the views of its intended users	6. The target users of the resource are clearly defined			
Domain 3	RIGOUR OF DEVELOPMENT	8 Items			
	Relates to the process used	7. Systematic methods were used to search for evidence			
	to gather and synthesise the evidence, the methods to	8. Criteria for selecting the evidence are clearly described			
	formulate the recommendations	9. Strengths and limitations of the body of evidence are clearly described			
	and to update them	10. Methods for formulating recommendations are clearly described			
		11. Health benefits, side effects, and risks have been considered in formulating the recommendations			
		12. There is an explicit link between the recommendations and the supporting evidence			
		13. The resource has been externally reviewed by experts prior to its publication			
		14. A procedure for updating the resource is provided			
Domain 4	CLARITY OF PRESENTATION	3 Items			
	Deals with the language, structure, and format of the resource	15. Recommendations are specific and unambiguous			
		16. Different options for management of the condition or health issue are clearly presented			
		17. Key recommendations are easily identifiable			
Domain 5	APPLICABILITY	4 Items			
	Pertains to the likely barriers and	18. Describes facilitators and barriers to its application			
	facilitators to implementation, strategies to improve uptake and resource implications of applying the resource	19. Provides advice and/or tools on how the recommendations can be put into practice			
		20. Potential resource implications of applying the recommendations have been considered			
		21. Presents monitoring and/or auditing criteria			
Domain 6	EDITORIAL INDEPENDENCE	2 Items			
	Formulation of recommendations not being unduly biased with competing interests	22. Views of the funding body have not influenced the content of the resource			
		23. Competing interests of resource development group members have been recorded and addressed			

Two overall resource assessment questions: rate the overall quality of this resource – Likert Scale 1–7: Lowest possible quality (1) to Highest possible quality (7). I would recommend this resource for use: Yes, Yes with modifications, No.

The term guideline has been changed to resource to encompass all the output from the data search

search including but not limited to, primary research studies, systematic reviews or meta-analyses, guidelines and policies, books, programmes and professional development and information-based resources, for example, factsheets, videos, websites and through consultation with experts in FASD, as outlined in table 3.

An iterative process will inform the comprehensive search approach.⁵ First, keywords will be identified by conducting an initial search of one bibliographic database and some grey literature to ascertain search terms and keywords that are utilised in the article title, abstract or study description. Next, we will identify synonyms of these keywords and subject headings for each database to be searched. Finally, advanced search syntax will be used to develop a search strategy for each database using the key terms and database-specific subject headings for example, Medical Subject Headings. Due to various website structures, each grey literature search will require bespoke consideration. Where possible, search terms will be combined in the same way as when conducting databases searches. Where multiple terms cannot be searched, the availability of primary and secondary navigation menus and/or basic search bars will be used to examine for relevant links and resources.

Consultation will then proceed with national/international experts in FASD by email or telephone. Consultations in the form of qualitative one-on-one phone interviews will be conducted to obtain information about any relevant resources for healthcare professionals, including unpublished resources, as well as any suggestions and contact details of other individuals or colleagues that may know of other resources. To track these strategies and searches, a concept table will be developed in excel for each database and website searched. The concept table will capture the name of the database, database coverage, date exported, reference management software (EndNote), total number of results and search strategy. Resources will then be imported into Covidence where any duplicates will be removed.

Search terms

The search terms and synonyms identified in table 4 will be modified and used for each database depending on the advanced search rules and search functions for respective databases. Truncations, wildcards, proximity, and Boolean operators will be used to expand on and combine these search terms to capture a broad range of possible resources and ensure a comprehensive search process.

Stage 4 and 5: evidence screening and selection

Resources will be imported into two reference management software systems (Endnote and Covidence). Evidence screening will commence with one member of the research team reviewing the titles and abstracts of studies following the inclusion criteria specified in table 2. A second reviewer will screen 20% of the titles and abstracts. The next step will involve obtaining full text for review of relevant evidence and screening for eligibility.¹⁸ This step will be conducted by two reviewers and additional reviewers will be available to resolve any disagreements or disparities in the screening process. The final step will involve one team member searching the reference lists of all identified reports and articles to identify any additional studies of potential relevance to be screened for eligibility using the inclusion criteria as done in the aforementioned steps.⁵

The study selection process, including the number of studies selected for inclusion in the final scoping review, will be described in a narrative description of the search process and a diagrammatic decision flowchart.¹⁸ A flow diagram as indicated in the PRISMA-ScR statement and checklist (figure 1) will be used to detail the screening and selection pf resources; including search results, removal of duplicate citations, study selection, retrieval of full-text articles and additional articles found in the reference list search.¹⁹ Detailed reasons will be provided for exclusion of articles.

Stage 6: evidence extraction (charting the data)

The data extraction stage in a scoping review is commonly referred to as charting the data, as results will be summarised in a logical and descriptive way in alignment with the review question(s) and objectives. Information and characteristics from the eligible resources such as references, authors, findings and results will be inserted into a charting table developed specifically for this scoping review and piloted for any refinement or modification of the tables that may be required. The pilot will involve two team members charting four randomly selected resources (two each) in an attempt to test the efficiency of the charting table for extracting all the relevant data of interest.⁵ The data charting tool used in this scoping review will be modified from the tool utilised by Lees *et at*^{$\dot{p}}$ in their scoping review of FASD resources for educators⁵ to suit our target sample of health professionals. Additional categories will be added from the JBI's recommended standardised extraction fields.²⁰ Data extraction is also an iterative process, often requiring multiple refinements in order to meet and address the research question(s) or study objectives. Therefore the charting table may need to be refined when conducting the full review.¹⁸ The draft data charting is outlined in table 5.</sup>

Quality appraisal

Assessment of resource quality will be undertaken using the AGREE II tool.²¹ The AGREE II comprises 23 items organised into six quality domains including scope and purpose, stakeholder involvement, rigour of development, clarity of presentation, applicability and editorial independence (table 6). Each of the 23 items addresses a different aspect of resource quality. At the end of the AGREE II appraisal tool, there are two questions that require each appraiser to give an overall judgement of the guideline or resource, considering how they have rated the 23 items. Each item will be allocated a score by the appraisers using a Likert scale ranging from 1 (Strongly Disagree) to 7 (Strongly Agree).

An overall quality grade will be calculated from the individual scores. The AGREE II manual document²¹ will be used to guide allocation and calculation of scores. Scoring will help identify limitations in the resource and select high-quality resources for recommendation, implementation and use in practice. Quality appraisal will be conducted by two members of the research team to ensure consistency and reliability of the process. Scoring differences will be assessed and considered by the two appraisers and when no consensus is reached, the larger research team will be involved to make a final decision. The AGREE PLUS is a platform that allows multiple users to complete, contribute to, coordinate and track appraisals online. This website operates using the email addresses of registered and invited researchers only, making it easier for multiple members to contribute to the appraisal process on one interface.

Stage 7: evidence (data) analysis

Analysis in a scoping review does not require data synthesis as used, for example, in reviews of quantitative data. Descriptive analysis of data extracted is advised and will be used for the current review.¹⁸ Descriptive analysis will collate frequency counts of populations, concepts, location of studies, type of resources, and so on which can then be mapped out for visual presentation using bar or pie charts, tables or word clouds as the research team deems fit. The way data are analysed is highly dependent on the purpose of the scoping review. For scoping reviews with a primary purpose of identifying concepts or clarifying definitions, qualitative descriptive analysis involving basic coding to set categories may be utilised with a thematic approach.^{22 23} However, given that the purpose of our review is to identify specific resources, basic descriptive analysis as described previously will be implemented.⁷

Stage 8: evidence (data) reporting and presentation

This scoping review will be reported in line with the (PRIS-MA-ScR) checklist²⁴ and a PRISMA flowchart (figure 1) will be used to show search results of the screening and selection process. Diagrammatic (bar/pie charts), descriptive or tabular formats will be used to report and present findings from the quality appraisal and charting stages, depending on the contents of included evidence. Data reported and presented will align with the objectives and scope of the review.

Stage 9: evidence summary

The main findings, including any concepts and the type of evidence available, will be summarised in relation to the review objectives. Relevance to key health professional groups will be considered and conclusions and recommendations made for future research and resource development based on identified gaps. In accordance with the aim of the review, outcomes will help identify resources that can be used by health professionals. To facilitate access to resources by Australian health professionals, any published, high-quality resources identified in the scoping review will be posted and freely available on the FASD Hub (www.fasdhub.org.au). The scoping review should be completed in 2022 and results will be published in a peer-reviewed publication and on the FASD Hub.

Patient and public involvement

The development of this research protocol did not require any involvement with patients or the public. However, during the scoping review process, consultation with experts in the diagnosis and management of FASD will occur to identify any additional, relevant resources not already included.

ETHICS AND DISSEMINATION

This is the first scoping review on this topic and will provide important insights for health professionals working with people with FASD. The methodological process is detailed and is guided by an established and referenced framework ensuring its reproducibility and transparency. Dissemination of data and results will be through conferences, peer-reviewed journals and relevant seminars to health professionals. Results from the review will also help inform the development of new resources to support health professionals. Scoping review is anticipated to be completed by the end of 2022 and results disseminated early in the year 2023. Ethical approval is not required for the scoping review.

 feedback on the protocol. JCO wrote the first draft of the review protocol which was revised and approved by LJR, EJE, EC, ST and LC. All authors have had training and experience in conducting systematic reviews, including use of checklists and as a result, were able to provide significant contributions.

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Competing interests EJE chairs the FASD Hub advisory board, and some authors have been involved in the development of some FASD resources. To address this, the identification and quality appraisal of resources will be conducted by two reviewers who are independent of the development of any such existing FASD resources.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting or dissemination plans of this research.

Patient consent for publication Not applicable.

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