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EAST MIDLANDS INTEGRATED LIFESTYLE (ILS) DATABASE - FEASIBILITY STUDY

Interim Report
November 2020

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Context

This project is a feasibility study to explore the development of an overarching Public Health Lifestyle dataset to support the services delivered by Local Authorities across the East Midlands. It is aimed at improving lifestyle and health outcomes. The project will consider the options for constructing such a dataset and will develop a delivery model for putting it in place.

Under the steer of the group of regional Directors of Public Health, chaired by Professor Derek Ward, the project will deliver the following:

Deliverables

- Scoping literature review
- Consultation exercise with key stakeholders to assess the feasibility and utility of an integrated lifestyle dataset
- Communication plan for dissemination of findings
- Position statement, delivery model and implementation plan
- Project report
- NIHR bid – highlighting key research questions to emerge from the feasibility study.

The timelines for the project are outlined in the Gantt chart at Appendix 1.

Progress to date

The project was formally logged with the University of Lincoln Ethics system on 16th September 2020.

Scoping Literature Review

The scoping literature review for public health lifestyle dataset feasibility studies **has been guided by** an appropriate framework (e.g Arksey and O'Malley, 2005), which allows for consultation with stake holders e.g key people in Local Authority and comprises the following steps:

- (i) Identifying the research question
- (ii) Identifying relevant studies
- (iii) Study selection
- (iv) Charting the data
- (v) Collating, summarizing and reporting the results
- (vi) Consultation

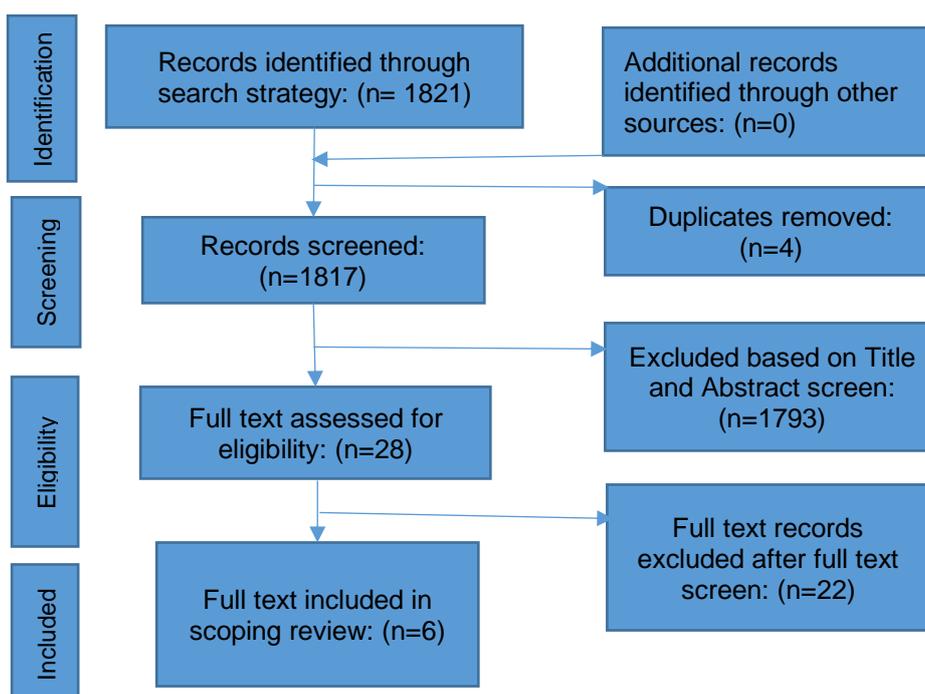
Using the search terms (public health AND (lifestyle OR "life style" OR life-style)) AND (database* OR dataset* OR "data set*") AND (feasib* OR develop* OR implement* OR use), we searched five electronic databases: Medline, CINAHL, Cochrane, Scopus, Psych-INFO. The reference lists of studies found through the searches were also checked for relevant studies using Google Scholar search. To select the relevant studies, we followed the PRISMA Extension for Scoping Reviews (PRISMA-ScR). Two reviewers independently screened the studies by title and abstract guided by the inclusion criteria. Any disagreement between the two reviewers over the eligibility of particular studies was resolved through discussion with a third reviewer. After the title and abstract screening, full texts of the eligible articles were retrieved and screened against the inclusion criteria:

Inclusion criteria:

- No limits to the publication dates since we were not sure of the extent of the evidence available.
- Only studies in the English language were included due to lack of funds for translating studies in other languages.
- Peer-reviewed academic literature
- Study design: quantitative, qualitative and mixed methods
- Any age group (adults and children)
- The focus was on any public health lifestyle data set
- Any geographical location

The study selection process is presented in the PRISMA flowchart (Fig 1) below

Figure 1: PRISMA flow chart representing the study screening process



Screening, selection of studies and extraction of data from selected studies was guided by a protocol which was designed by the research team and agreed with the funders (Please see appendix 2). Pending a full literature review report, below is an annotated bibliography covering 6 studies that resulted from the study selection process above and included in the review.

Included studies

1. Saunders P, Mathers J, Parry J, Stevens A. (2001). "Identifying 'non-medical' datasets to monitor community health and well-being." *Journal of Public Health* 23(2): 103-108. <https://doi.org/10.1093/pubmed/23.2.103>

In this study, a stakeholder discussion involving public health and environmental health academics and professionals, and an interrogation of the Office for National Statistics database were carried out for the West Midlands region. The aim was to identify routinely collected 'non-medical' datasets containing information on physical environment, crime, housing and homelessness, social services, socio-economic environment including employment, lifestyles, education, leisure and culture, transport and accidents.

Although the authors collected information on a variety of datasets, the lifestyle data (particularly smoking and drinking data from the Health Survey for England dataset) is relevant to our study which focuses on only lifestyle datasets. Saunders et al. suggested that inter-sectoral working and multi-agency involvement at the local level can improve the quality of many datasets and can promote their use in the measurement and monitoring of community health. Hence, encouraging local authority collaboration in data collection and sharing can make it feasible to develop and implement an integrated lifestyle database for the East Midlands region.

2. Zwisler AD, Rossau HK, Nakano A, et al. The Danish Cardiac Rehabilitation Database. *Clin Epidemiol.* 2016; 8:451-456. Published 2016 Oct 25. doi:10.2147/CLEP.S99502.

This study is about the Danish Cardiac Rehabilitation Database (DHRD), an online, clinical quality database that aims to ward provide higher quality CR for patients with CHD in Denmark. The process of implementation of this database is relevant and can inform the development and implementation of an East Midlands integrated lifestyle database. This is because, the DHRD systematically monitors the quality of Cardiac Rehabilitation provision across programmes over time and data can be assessed as a part of research related to both the outcome and organization of Cardiac Rehabilitation. Some of the variables recorded in the DHRD include smoking status, exercise capacity, height, weight and blood pressure; and data on performed diagnostic tests (eg, diabetes and depression), along the individual plan for rehabilitation (eg, training sessions, dietary

treatment, and/or smoking cessation). This approach can inform the plan for development and implementation of the East Midlands lifestyle database.

3. Lakervield J, Loyen A, Ling FCM, et al. Identifying and sharing data for secondary data analysis of physical activity, sedentary behaviour and their determinants across the life course in Europe: general principles and an example from DEDIPAC. *BMJ Open* 2017;7: e017489. doi: 10.1136/bmjopen-2017-017489

Lakervield et al. (2017) described the inventory, development of a comprehensive European dataset and the process towards cross-European secondary analyses of pooled data on physical activity and sedentary behaviour. To do this the authors applied the Findable; Accessible; Interoperable; Reusable (FAIR) framework to provide guidance in the discovery and reuse of data for further investigation, and followed a five-step methodology: (1) identification of relevant datasets across Europe, (2) development of a compendium including details on the design, study population, measures and level of accessibility of data from each study, (3) definition of key topics and approaches for secondary analyses, (4) process of gaining access to datasets and (5) pooling and harmonisation of the data and the development of a data harmonisation platform.

The study has demonstrated that it is possible to retrieve from lifestyle data (e.g physical activity and sedentary behaviour) using the variables: type of variables, age groups under study, study design, type of measurement instruments used, time frame, etc. This suggests that the development and integration of an East Midlands lifestyle database may be feasible. However, Lakervield et al. (2017) noted barriers such as limited potential for reuse and the variation in assessment methods and operationalisation of outcome variables across current European studies hampered data harmonisation. However, improving data collection and management by consistent data collection methodologies for example, and applying an appropriate model of implementation such as the FAIR principles, could help address the barriers and make lifestyle data integration in East Midlands possible.

4. Clarke A & Steele R. "Summarized data to achieve population-wide anonymized wellness measures," 2012 Annual International Conference of the IEEE Engineering in Medicine and Biology Society, San Diego, CA, 2012, pp. 2158-2161, doi: 10.1109/EMBC.2012.6346388.

Clarke and Steele (2012) discussed some of the technologies that increase the ease and capability of gathering quantitative wellness data via smartphones, how specific and detailed the data should be for public health use and the challenges associated with such anonymised data collection. They then proposed a framework to facilitate the collection of non-identifying data; this is based on increased local processing so that only the required information is submitted to avoid the risk of re-

identification. There is also anonymous submission network which removes the potential for re-identification through the communication layer. While this paper does not directly deal with the development and implementation of an integrated database, it is relevant because lessons may be learnt from the proposed framework to inform the collection and integration of anonymised lifestyle datasets in the East Midlands.

5. Sarkar C, Webster C, Gallacher J. UK biobank urban morphometric platform (UKBUMP) - a nationwide resource for evidence-based healthy city planning and public health interventions. *Ann GIS*. 2015; 21:135–48.

Sarkar et al. report the development of a seminal UK-wide baseline spatial database that will function as a platform for evidence-based healthy city planning and will facilitate the construction of suite of models to explicitly decipher health impacts from the genetic to micro built environment scales for half-a-million Britons. The authors introduce the urban health niche paradigm, as a holistic and multidisciplinary approach to studying healthy city dynamics, with potential pathways through which gene-environment may interact to produce a functional niche for cardiovascular diseases in a city. Together, the conceptual and empirical data models provide a basis for multilevel urban planning and health policies and intervention strategies at both individual and population levels, allowing for a much greater accuracy of evidence-based policy-making.

While this study focuses on built environment, some aspects relate to the importance of our planned lifestyle database for East Midlands, that we can draw on. For example, it is clear from the study that the quality and extent of local environmental exposures influences individual physical activity behaviour, lifestyle and social interactions, general well-being and consequently, specific health outcomes including weight outcomes, stress levels, cardio-metabolic and mental health risks.

6. Li, Sixuan et al. “Surveillance of Noncommunicable Disease Epidemic Through the Integrated Noncommunicable Disease Collaborative Management System: Feasibility Pilot Study Conducted in the City of Ningbo, China.” *Journal of medical Internet research* vol. 22,7 e17340. 23 Jul. 2020, doi:10.2196/17340

This was a pilot study conducted in Ningbo city by the Chinese Center for Disease Control and Prevention (CDC) with the aim of developing an innovative model for NCDs surveillance and management: the integrated noncommunicable disease collaborative management system (NCDCMS). This Ningbo model was designed and developed through a 3-level (county/district, municipal, and provincial levels) direct reporting system based on the regional health information platform. The uniform data standards and interface specifications were established to connect different platforms and conduct data exchanges, allowing for automatic NCDs data exchanging and

sharing. According to the authors, the NCD CMS completely reshaped the process of NCD surveillance reporting and had unique advantages, which include reducing the work burden of different stakeholders by data sharing and exchange, eliminating unnecessary redundancies, reducing the amount of underreporting, and structuring population-based cohorts. The Ningbo model is expected to be a milestone in NCDs surveillance, control, and prevention in China. Hence, this approach could be promoted or adopted to inform the development and implementation of an integrated lifestyle database for East Midlands taking into consideration local factors.

Conclusion from scoping review

Evidence from the 6 studies included in the review indicates that several databases were developed or implemented in and outside the UK, but no integrated lifestyle database appears to exist in the East Midlands regions.

The review also revealed that using an appropriate model such as the Findable, Accessible, Interoperable and Reusable (FAIR) principles and taking into consideration local factors, could facilitate the development and implementation of a database. This may be applicable to the implementation of an integrated lifestyle database for East Midlands. However, the evidence from this literature review would need to be explored further with stakeholders in East Midlands using a consultation approach.

Consultation exercise with key stakeholders to assess the feasibility and utility of an integrated lifestyle dataset

We were commissioned to conduct a consultation exercise with key stakeholders to assess the feasibility of developing an East Midlands Integrated Lifestyle Service Database including any potential issues with data access/collation and sharing and the potential usability of such a dataset to Local Authorities.

The consultation exercise is currently underway.

Preliminary work involved the identification and agreement about the key personnel and organisations who would be the first point of contact across the five Local Authorities in the East Midlands to be invited to take part in the consultation and identify other appropriate colleagues to involve.

A template to guide the content of the interviews (informed by the literature) was devised and sent to a representative of the Integrated Lifestyle service in Lincolnshire for comment. This informed slight modification of the tool which was then agreed with the funders before being utilised for the consultation exercise. A copy is included as Appendix 4.

An invitation to a consultation exercise was sent out and although there has been a slow response due to the Covid-19 pandemic related workload on Local Authorities, the following stakeholders have so far responded and participated in the consultation exercise which has been arranged by email (including in some cases the completion of information/response to questions on the interview guide) and followed up by a virtual meeting via MS TEAMS.

:

- Lincolnshire (Lincolnshire County Council, represented by the Head of service, Thrive Tribe/OYL) - responded to questions on interview guide on 22/10/2020.
- Nottinghamshire (3 attendees: a consultant of public health, Senior Public Health and Commissioning Manager and a health improvement principal) – consultation meeting held on 02/11/2020
- Leicestershire (Integrated Lifestyle Manager- Public Health) – consultation meeting held on 02/11/2020.
- Derby have responded to questions on interview guide on 11/11/2020.
- Northamptonshire has not yet responded, but Sally has been very supported and has provided several email contacts. Hopefully, we would hear from one of the contacts we have recently emailed.

Pending a full report when the consultation exercise is completed, the following key points are coming through:

- Service providers, in general, would embrace a shared dataset across the East Midlands – as it would add value to service delivery and best practice
- A shared East Midlands lifestyle dataset will also be useful for research to inform policy and service improvement
- There are existing lifestyle datasets across smoking, alcohol consumption etc (e.g OYL/Thrive Tribe lifestyle service in Lincolnshire) that can be shared
- It could be expensive to migrate from current dataset to a new integrated dataset
- It depends on what we find in terms whether all the regions are using the same technology and collecting exactly same variables in order to create an integrated dataset. It would be like much less trouble than starting from scratch, which would be very expensive
- Can be expensive to standardise software and approaches, reluctance of companies to share their private commercial products, commissioner expectations and demands vary wildly from boroughs, council and localities and services are collecting very different levels of data.
- Lifestyle service providers seem to be in competition for clients and may not want to data share because of fear of revealing their service provision strategy

- Need to consult with GPRCC, NHS Digital and other external data partners or controllers in planning to develop and implement an integrated database
- Not every service is set up or commissioned in the same way.
- Depends resource (availability)

Some questions are arising such as:

- How willing would people be on signing up to this? Or is this an assumption on a voluntary sort of basis where some services would, and some wouldn't?
- Would it be mandatory, or would it be voluntary? If some areas are not going to produce results or submit results or whatever, then how useful is the whole exercise going to be when you're comparing different regions and services etc.

Alongside the consultation exercise, we are developing the Traffic Light system (Avery et al., 2017) which will be used to support our decision about feasibility at the end of the study. Details of the Traffic Light system is in Appendix 5.

Communication plan for dissemination of findings

We have not agreed on this yet but we are exploring the following:

- Interim and final report to the funder through Sally Bassett and Prof Derek Ward
- Workshops/meetings with stakeholders to share findings
- Conference and seminar presentations
- Peer review journal papers

Position statement, delivery model and implementation plan

Indicative thoughts at this stage

The evidence from the literature review suggests, guided by an appropriate model, and taking into consideration local factors, an East Midlands integrated lifestyle database could be developed and implemented. Findings from the consultation exercise (so far) suggests that stakeholders would welcome an East Midlands integrated lifestyle database. However, there are concerns relating to potential barriers to dataset sharing. Therefore, further research is needed to more extensively explore the views of stakeholders (including service providers and users; public health practitioners/consultants and commissioners; database and IT managers; business intelligence etc) on the barriers and facilitators to the development and implementation of an integrated lifestyle database in East Midlands.

NIHR bid – highlighting key research questions to emerge from the feasibility study.

- A Bid is being developed for NIHR funding – deadline 7th January 2021 as detailed here: <https://www.nihr.ac.uk/funding/20114-unlocking-data-to-inform-public-health-policy-and-practice/25939>
- Prof Derek Ward, Prof Graham Law and a service users have confirmed they are happy to be coapplicatns – and this work is progressing.
- We have also just secured £10066 funding from the university to support this project

References

Arksey H & O'Malley L (2005) Scoping studies: towards a methodological framework. *Int J Soc ResMethodol* 8(1):19–32.

Avery KNL, Williamson PR, Gamble C, et al. (2017) Informing efficient randomised controlled trials: exploration of challenges in developing progression criteria for internal pilot studies. *BMJ Open*;7: e013537.

Clarke A & Steele R. (2012) "Summarized data to achieve population-wide anonymized wellness measures," 2012 Annual International Conference of the IEEE Engineering in Medicine and Biology Society, San Diego, CA, 2012, pp. 2158-2161.

Lakerveld J, Luyen A, Ling FCM, et al. (2017) Identifying and sharing data for secondary data analysis of physical activity, sedentary behaviour and their determinants across the life course in Europe: general principles and an example from DEDIPAC. *BMJ Open*;7: e017489.

Li, Sixuan et al. (2020) "Surveillance of Noncommunicable Disease Epidemic Through the Integrated Noncommunicable Disease Collaborative Management System: Feasibility Pilot Study Conducted in the City of Ningbo, China." *Journal of medical Internet research* vol. 22,7 e17340.

Saunders P, Mathers J, Parry J, Stevens A. (2001). "Identifying 'non-medical' datasets to monitor community health and well-being." *Journal of Public Health* 23(2): 103-108.

Sarkar C, Webster C, Gallacher J. (2015) UK biobank urban morphometric platform (UKBUMP) - a nationwide resource for evidence-based healthy city planning and public health interventions. *Ann GIS*. 21:135–48.

Zwisler AD, Rossau HK, Nakano A, et al. (2016) The Danish Cardiac Rehabilitation Database. *Clin Epidemiol*. 2016; 8:451-456.

Appendices

Appendix 2: Protocol for screening, selection of studies and extraction of data from selected studies.

Introduction

The social care legislation (Health and Social Care Act, 2012) places specific duties on county councils to protect and promote health, and reduce health inequalities. Local authorities across the East Midlands deliver lifestyle services to communities, which include smoking cessation, improvement in diet, reduction in physical inactivity and reduction in alcohol consumption. While some authorities offer stand-alone services, others have implemented innovative integrated service models.

In the pursuit of improved health outcomes authorities are evaluating their services through a range of approaches. The national evidence base needs enhancing to drive improvement and efficiency. This could be done by exploring the potential to have one integrated dataset bringing together information on public health lifestyle interventions across the East Midlands. This review will explore the literature for evidence of whether it is feasible to develop and implement an integrated public health lifestyle data set in the East Midlands. The objectives of the review will include:

- To map the existing peer-reviewed literature on feasibility of implementing a public health lifestyle data set
- To determine the type and extent of the evidence available
- To identify any gaps for further research

METHODS

We will follow Arksey and O'Malley's framework for this scoping review: identifying the research question; identifying relevant studies; selecting the studies; charting the data; collecting, summarising and reporting results (Arksey & O'Malley, 2005).

Identifying the research question

The review will address the question: What is known about the development and implementation of a public health lifestyle data set?

Identifying relevant studies (Searches)

The following inclusion and exclusion criteria will guide the search strategy.

Inclusion criteria:

- There will be no limits to the publication dates since we are not sure of the extent of the evidence available.

- Only studies in the English language will be included due to lack of funds for translating studies in other languages.
- Peer-reviewed academic literature
- Study design will be quantitative, qualitative and mixed methods
- Any age group (adults and children)
- The focus will be on any public health lifestyle data set
- Any geographical location

Exclusion criteria:

- Studies not in the English language
- Non-peer reviewed literature
- Non-public health lifestyle data set

Using the search terms (public health AND (lifestyle OR "life style" OR life-style)) AND (database* OR dataset* OR "data set*") AND (feasib* OR develop* OR implement* OR use), we will search the following electronic databases (Medline, CINAHL, Cochrane, Scopus, Psych-INFO).The reference lists of studies found through the electronic database searches will be checked for relevant studies using Google Scholar search.

Selecting the studies

We will follow the PRISMA Extension for Scoping Reviews (PRISMA-ScR). Two reviewers will independently screen all titles and abstracts in line with the inclusion and exclusion criteria. Any disagreement between the two reviewers over the eligibility of particular studies will be resolved through discussion with a third reviewer. After the title and abstract screening, full texts of the eligible articles will be retrieved and screened. The study selection process will be presented in a PRISMA flowchart.

Charting the data

The data will be charted according to an analytical framework that will facilitate sorting the material into a data extraction table. The table will be created by the research team to meet the study objectives. Data will be charted by one researcher (JA) and will be checked by two members of the research team (RK and HH). Standard information such as authors, year of publication, study setting, aim, methods, study population, findings and country/location will be extracted from all included articles and charted.

Collating, summarising and reporting results

The findings from the included studies will be collated, summarised into themes using a thematic analysis approach. This will initially be done by one reviewer (JA) and then checked by two members of the research team (RK and HH). We will not conduct a quality appraisal of the included studies since scoping reviews usually aim to only provide a descriptive account of the evidence (Coughlan & Cronin, 2017).

References

Arksey H, O'Malley L (2005) Scoping studies: towards a methodological framework. *Int J Soc ResMethodol* 8(1):19–32.

Coughlan M, Cronin P (2017) *Doing a literature review in nursing, health and social care*, 2nd edn. SAGE, London.

Health and Social Care Act 2012, c.7. Available at:

<https://www.legislation.gov.uk/ukpga/2012/7/contents/enacted> (Accessed: 20/09/2020).

Appendix 3: Details about the 22 studies which were excluded from the review.

Excluded studies after full text screen

The 22 studies listed below were generated from the systematic search strategy, but these did not relate to datasets involving any of the lifestyle of interest: smoking, alcohol consumption, physical activity and diet & exercise.

1. Kinsner-Ovaskainen A; Lanzoni M; Garne E; Loane M; Morris J; Neville A; Nicholl C; Rankin J; Rissmann A; Tucker D; Martin S. A sustainable solution for the activities of the European network for surveillance of congenital anomalies: EUROCAT as part of the EU Platform on Rare Diseases Registration. *European journal of medical genetics*. 2018 Sep
2. Ordoñana JR; Carrillo E; Colodro-Conde L; García-Palomo FJ; González-Javier F; Madrid-Valero JJ; Martínez Selva JM; Monteagudo O; Morosoli JJ; Pérez-Riquelme F; Sánchez-Romera JF. An Update of Twin Research in Spain: The Murcia Twin Registry. *Twin research and human genetics: the official journal of the International Society for Twin Studies*. 2019 Dec
3. Thompson ML; Miller RS; Williams MA. Construction and characterisation of a longitudinal clinical blood pressure database for epidemiological studies of hypertension in pregnancy. *Paediatric and perinatal epidemiology* 2007 Nov
4. Godderis L; Mylle G; Coene M; Verbeek C; Viaene B; Bulterys S; Schouteden M. Data warehouse for detection of occupational diseases in OHS data. *Occupational medicine (Oxford, England)* 2015 Nov
5. Sugiyama T; Miyo K; Tsujimoto T; Kominami R; Ohtsu H; Ohsugi M; Waki K; Noguchi T; Ohe K; Kadowaki T; Kasuga M; Ueki K; Kajio H. Design of and rationale for the Japan Diabetes compREhensive database project based on an Advanced electronic Medical record System (J-DREAMS). *Diabetology international* 2017 Jun 27
6. Ogushi Y; Haruki Y; Okada Y; Takahashi M; Shimizu M; Izumi Y; Watabe T; Kobayashi S; Okuyama J; Kurita Y. Development and evaluation of regional health database systems. *Studies in health technology and informatics*. 1998 –book chapter
7. Austin MA; Harding S; McElroy C. Genebanks: a comparison of eight proposed international genetic databases. *Community genetics* 2003
8. Baus A; Wood G; Pollard C; Summerfield B; White E. Registry-based diabetes risk detection schema for the systematic identification of patients at risk for diabetes in West Virginia primary care centers. *Perspectives in health information management*. 2013 Oct 01 - (*might be useful*)
9. Howell NA; Tu JV; Moineddin R; Chen H; Chu A; Hystad P; Booth GL. The probability of diabetes and hypertension by levels of neighbourhood walkability and traffic-related air pollution across 15 municipalities in Southern Ontario, Canada: A dataset derived from 2,496,458 community dwelling-adults. *Data in brief* 2019 Aug 28
10. Hwee L.J., Witarsyah D., Kasim S., Fudzee M.F.M. Healthy food intake advisor using decision support system 2020
11. Armstrong J., Rudkin J.K., Allen N., Crook D.W., Wilson D.J., Wyllie D.H., O'connell A.M. Dynamic linkage of covid-19 test results between public health England's second generation surveillance system and uk biobank 2020
12. Prosperi M., Min J.S., Bian J., Modave F. Big data hurdles in precision medicine and precision public health 2018 *BMC Medical Informatics and Decision Making*

13. Yoo H., Chung K. Mining-based lifecare recommendation using peer-to-peer dataset and adaptive decision feedback 2018 Peer-to-Peer Networking and Applications. (??exclude)
14. Doiron D., Burton P., Marcon Y., Gaye A., Wolffenbuttel B.H.R., Perola M., Stolk R.P., Foco L., Minelli C., Waldenberger M., Holle R., Kvaløy K., Hillege H.L., Tassé A.-M., Ferretti V., Fortier I. Data harmonization and federated analysis of population-based studies: The BioSHaRE project 2013. Emerging Themes in Epidemiology
15. Sak J., Pawlikowski J., Goniewicz M., Witt M. Population biobanking in selected European countries and proposed model for a Polish national DNA bank 2012 Journal of Applied Genetics
16. Malmberg G., Nilsson L.-G., Weinehall L. Longitudinal data for interdisciplinary ageing research. Design of the Linnaeus Database 2010 Scandinavian Journal of Public Health
17. Hansen W., Kalapasev N., Gillespie A., Singler M., Ball M. Development of a pedestrian walkability database of northern Kentucky using Geographic Information Systems (GIS) 2009. Journal of Physical Activity and Health
18. Mauri D., Pazarlis P., Mauri J., Altinoz H., Rivas Flores F.J., Karentzou I., Proiskos A., Lakiotis V., Maragkaki A., Terzoudi E., Dambrosio M., Spiliopoulou A., Varsami A., Alexandropoulou P., Tolis C., Pavlidis N., Vittoraki A. SESy-Europe: A multi-language database dedicated to cancer screening monitoring 2004 Journal of Experimental and Clinical Cancer Research
19. Godard B., Marshall J., Laberge C., Knoppers B.M. Strategies for Consulting with the Community: The cases of four large-scale genetic databases 2004 Science and Engineering Ethics
20. Austin M.A., Harding S., McElroy C. Genebanks: A comparison of eight proposed international genetic databases 2003Community Genetics. (? Exclude)
21. Stern R.M., Tarkowski S. The need for a unified European environmental health database. 1990, Information Services and Use
22. Ng N; Van Minh H; Tesfaye F; Bonita R; Byass P; Stenlund H; Weinehall L; Wall S. Combining risk factors and demographic surveillance: potentials of WHO STEPS and INDEPTH methodologies for assessing epidemiological transition. Scandinavian Journal of Public Health. Mar2006.

Appendix 4: Data collection tool utilised during the consultation exercise.



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East Midlands Integrated Lifestyle (ILS) service Database- feasibility study

Topic guide

September 2020

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This project is a feasibility study to explore the development of an overarching Public Health Lifestyle dataset to support the services delivered by Local Authorities across the East Midlands, with the aim of improving lifestyle and health outcomes. The project will consider the options for constructing such a dataset and will develop a delivery model for putting it in place. Focusing on four key lifestyle areas (smoking cessation, reduction in alcohol consumption, reduction in physical inactivity and diet/weight management, the following questions will guide a consultation exercise with stakeholder.

Please write your responses in the space provided if you wish to

Background questions

1. Your local authority.....
2. Your current role.....
3. We have identified the following key public health lifestyle interventions:
 - Smoking cessation
 - Reduction in physical inactivity
 - Reduction in alcohol consumption
 - Diet/weight management

Are there any other key lifestyle areas that may be added?

Questions on datasets

4. How do you currently use lifestyle intervention datasets? (*Implementation*)

.....
.....

5. Are you willing to share details of the template (a blank lists of variables) used to collect data across the lifestyle areas, so we can determine whether the variables can be linked to form one database? (*Expansion*)

.....
.....

6. Do you have any examples of datasets that can be shared - to show how the variables are mapped out/collected? (Expansion, adaptation)

.....
.....

7. What datasets exist in your area/that you are aware of? (*Practicality*)

.....
.....

8. Are the datasets in your area separate (for different lifestyles: smoking cessation, alcohol consumption, reduction in physical inactivity and diet/weight management) or integrated? (*Integration*)

.....
.....

9. How are the datasets used to inform service development? (*Demand, Implementation*)

.....
.....

10. How can a shared dataset fit into your lifestyle service? (*Integration*)

.....
.....

11. How can an existing dataset be modified for shared use across East Midlands? (*Adaptation*)

.....
.....

Questions about ownership/storage/sharing agreements with datasets

12. How useful would a shared data set across the whole East Midlands be? (*Acceptability, demand, limited efficacy*)

.....
.....

13. What are the advantages and disadvantages of a shared dataset? (*Practicality*)

.....
.....

14. Are there any barriers to creating an East Midlands wide dataset? If yes, what are they? (*Practicality*)

.....
.....

15. What factors will facilitate the implementation of a shared dataset across East Midlands?
(*Practicality*)

.....
.....

16. Who are the datasets used by? (*Acceptability, Demand*)

.....
.....

17. How cost effective will a shared dataset across East Midlands be? (*Practicality*)

.....
.....

18. How is evidence base used (how can it be used) to steer decision making in your organisation
(*practicality*)?

.....
.....

19. Who else should we be speaking to in your organisation?

.....
.....

20. Where are data shared already and with whom?

.....
.....

21. Any further comments on developing and implementing a shared dataset in East Midlands?

.....
.....

THANK YOU FOR YOUR TIME AND SUPPORT

Appendix 5: The Traffic light system (Avery et al., 2017)

The Traffic Light system (Avery et al., 2017) suggests that instead of employing a simply stop/go criteria, it is more useful to employ a red/ amber/ green Traffic Light progression criteria to explore whether the project should move into a future phase of dataset development. This is outlined as follows:

- stop/red (when there are intractable issues that cannot be resolved),
- amend/amber (where there are remediable issues in which modifications may be needed before progressing) continue/green (where no concerns have arisen that threaten the success of the proposed intervention – in this case the development of the dataset)

Table 1 Summary of feasibility findings showing progression decision for each feasibility outcome and proposed modifications for each outcome (blank table for now).

Outcome		Decision	Summary of proposed modifications
Acceptability		Insert traffic light	
Demand			
Implementation			
Practicality			
Adaptation			
Integration			
Expansion			
Limited efficacy			