SURVEY REPORT 2020

MRC / VERSUS ARTHRITIS
SPF ADVANCED PAIN DISCOVERY
PLATFORM

SURVEY

**APDP
RESEARCH
DATA HUB**

UKRI Medical Research Council

VERSUS ARTHRITIS

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Survey Approach

The survey results detailed within this document have been culminated from the; MRC Research Data Hubs Survey for the SPF Advanced Pain Discovery Platform Programme (APDP) that was sent to all identified UKRI and Versus Arthrits APDP stakeholders. The survey was also advertised on; the APDP Web-page (https://mrc.ukri.org/research/initiatives/advanced-pain-discovery-platform-apdp/), Versus Arthritis webpage, as well as through social media channels. A link to the survey was also inserted into the pre-call announcement for the mental health and pain research data hub call.

The Survey was live from 12th - 25th of November.

Introduction

As a part of the MRC/Versus Arthritis SPF Advanced Pain Discovery Platform (APDP) initiative, we are developing a call for proposals to support the establishment of a pain research data hub that will be embedded within the broader infrastructure and network of health data research UK. The aim is to establish the data hub as a platform that will bring together, and provide open access to, existing data, as well as, all data and results from across the APDP investments including; the large consortia and research programmes. This will provide a key national resource for the pain research community to tackle the long-term research challenges in understanding the complexity and unpredictability of pain and, reveal new and improved treatments across diverse chronic and debilitating pain conditions.
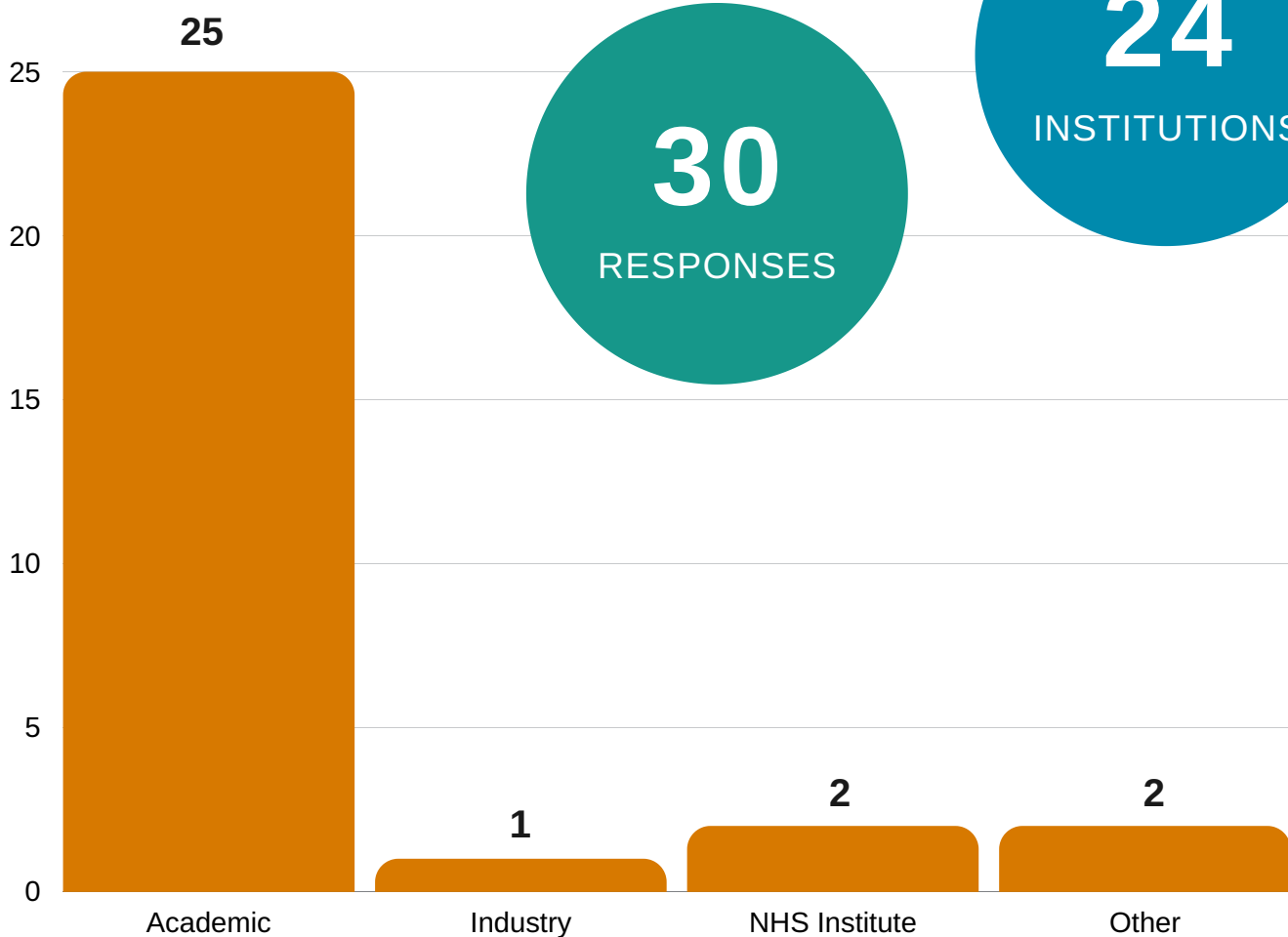
The hub will facilitate working across different types of data (molecular, cellular, phenotypic, health data etc) and will support industry partnerships, thereby helping to drive translation to health improvements.

A draft specification for the APDP Research Data Hub was shared with survey respondents as part of this consultation phase. Respondents provided feedback and comments on key aspects of this specification.
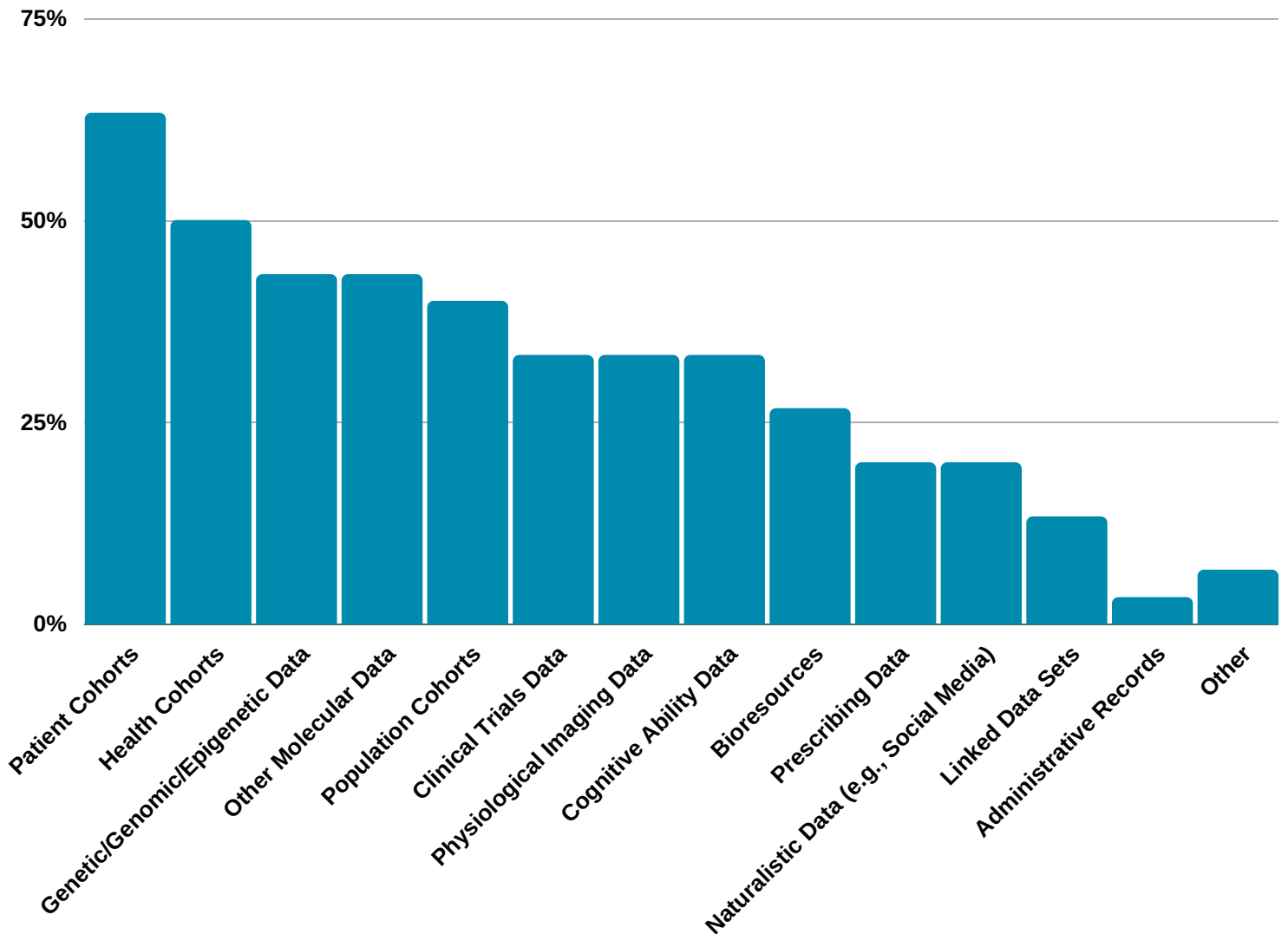
Following the consultation phase, a call for the APDP pain research data hub has been launched with updated specifications. This call can be found here https://www.ukri.org/opportunity/pain-research-data-hub/

SURVEY RESULTS

30 RESPONSES

24 INSTITUTIONS

25	

25

20

15

10

5

0

25 — Academic

1 — Industry

2 — NHS Institute

2 — Other

TYPES OF DATA SETS CURRENTLY USED BY RESPONDENTS

Other*

- Chronification in pain
- Longitudinal data
- Pain in neurodegeneration
- Biologics registries

It is proposed that the pain research Data Hub should initially prioritise the data it makes available and the services it provides based on a defined vision that addresses areas of greatest need/opportunity and aligns with the strategic ambitions of the APDP initiative. Core to the APDP initiative is to support research that furthers our understanding of pain mechanisms and pathways. Through a multidisciplinary approach the APDP aim to provide new knowledge about the significant variation and unpredictability that exists in the lived experience of pain and uncover shared mechanisms, across social, psychological and biological dimensions.

SPF APDP DATA HUB DRAFT SPECIFICATION SURVEY QUESTIONS

IMPACT & USABILITY

Areas of focus prioritised by those that may be most impactfully advanced by increased access and usability of data across multiple sources over the 3 year establishment phase of the hub. (up to three areas selected by each respondent).

6.7%

Explore treatments outside of drug discovery.

18.9%

Further explore links between specific phenotypes and mechanistic targets.

15.6%

Understand what data is already accessible and optimise its use by building on existing tools and resources.

14.4%

Stratification of patients and pain phenotypes to improve the clinical definition of pain.

30%

The year 2016 and subsequent years will undoubtedly bring their own challenges and business opportunities. We are moving forward from a solid strategic position

8.9%

Standardisation across the field on how pain is reported or published including better defined outcome measures.

4.4%

Capture negative results from studies so learnings can help drive and refine areas of potential interest.

17.8%

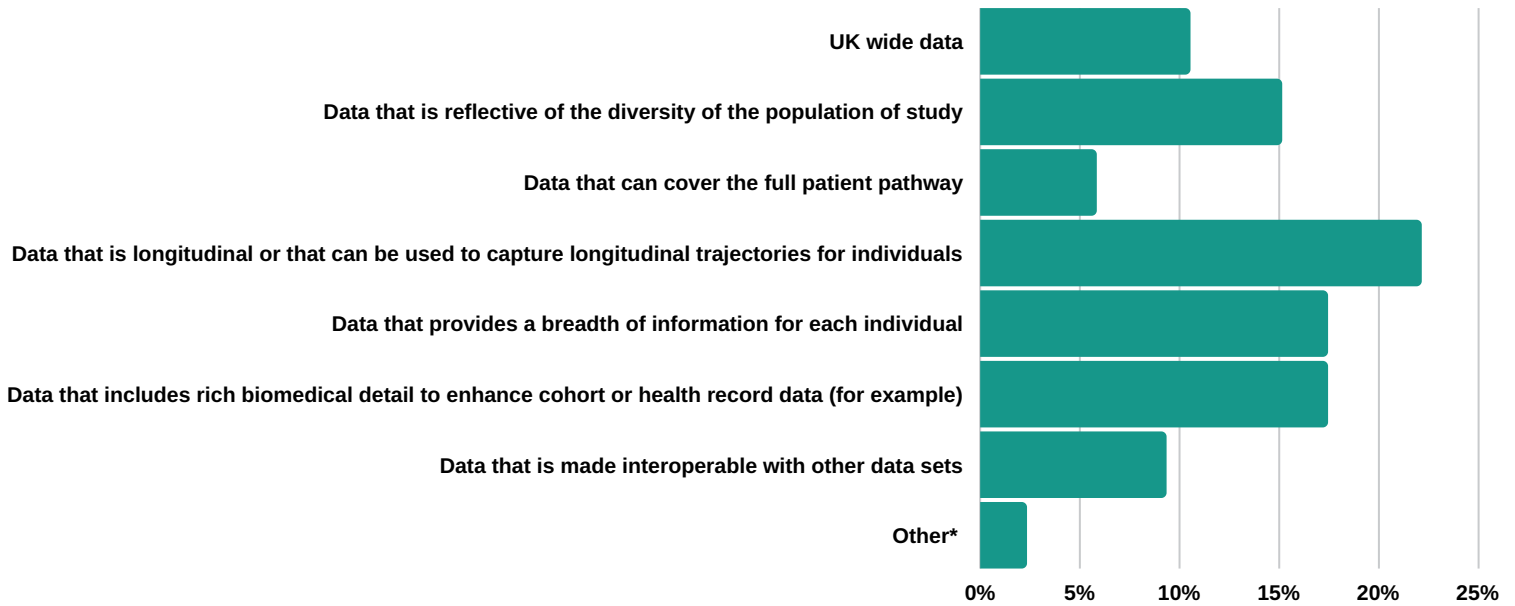Identify and develop new targets and treatments.

11.1%

Improve target validation and the potential for drug repurposing.

2.2%

Other - Disseminate and spread pain related knowledge widely, Gain mechanistic insight into pain by bridging data analysis across multiple cohorts.

INITIAL DATA SETS

The initial data sets will be driven by the prioritised challenges. However, respondents were asked to comment on what data qualities would add most value to pain research for the themes they selected in the preceding impact and usability question. Respondents selected up to three responses from the list provided.
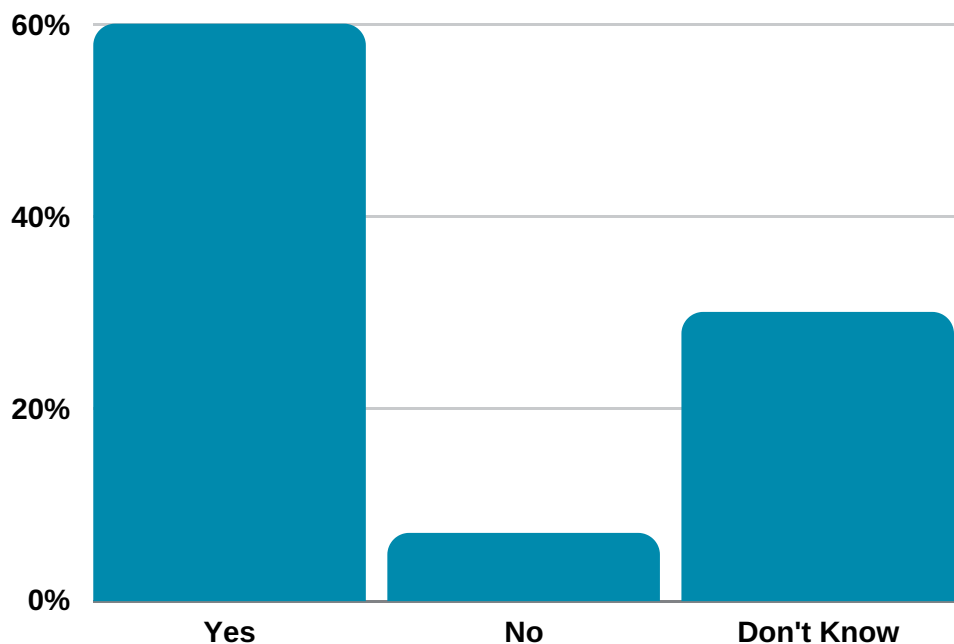

Other*

Personalized data: on active attempts by the person in pain to reliably record their data, epigenetic immunogenomics t and b-cells data must link to work done at EU level ERanets/IMI

ACCESS COST

Respondents were asked whether they would happy to pay a reasonable cost should one be associated with the above services

DISCOVERABLE DATA

It is expected that the Hub will make data discoverable via the HDR UK Gateway andwill also curate data and provide services to improve its use for research.

RESPONDENTS RANKED POTENTIAL SERVICE OFFERINGS

1

Identification of individuals for clinical trials or research studies.

2

Curation of bespoke data sets.

3

Assess feasibility and provide support on study design and analysis.

4

PPI engagement workshops. Bringing the lived experience perspective to facilitate legitimate data access requests.

5

Providing test and validation data sets.

6

Work with data controllers and custodians to make safe sharing of pain research data easier

7

Help navigate UK pain research data. Assist with regulatory and data access procedures.

8

Providing (and developing) open access tools and methods for use in pain research data science.

9

Facilitating multi-site data research across the UK.

10

Enhance and supplement data sets to enable broader questions to be addressed. Harmonising key data sets to enhance their interoperability.

11

Establishing key data linkages to allow key outcomes to be identified and a more comprehensive picture of the mechanisms of pain.

APDP Pain Research
Data Hub Draft Specification

This call for funding is to support the establishment of a pain research data hub over 3 years. It is anticipated that the Hub will continue to grow in scale and ambition beyond the 3 years, evolving into a coordinated and integrated national resource for pain research. It is expected that the Data Hub will:

- Act as a centre of excellence for curation of pain research data at scale and provide UK wide expert research data services

- Improve the quality, breadth and depth of datasets and provide a repeatable curation approach that can be used to enable UK-scale research.

- Create globally leading data sets and make these discoverable and accessible to researchers and other users in areas of greatest opportunity.

- Provide services to meet the needs of researchers, NHS, industry, charities, innovators and ultimately patients and the public.

- Enable real world insights, innovations and improvements in care not currently possible without data at this scale.

- Improve secure access to data through membership of the UK Health Data Research Alliance (the 'Alliance') and use of the UK Health Data Research Innovation Gateway (the 'Gateway').

APDP Pain Research
Data Hub Draft Specification

- Harness opportunities to work across the HDR UK Data Innovation Hub network.

- Embed patient and public involvement in development of the Hub to ensure it is driven by the needs of people with lived experience of pain.

- Have strong leadership, deep domain expertise and governance, including plans for including patients and members of the public in decision-making and governance and how the Hub will ensure that research outcomes from its work are linked to patient benefits

- Designed with capacity to evolve and be responsive to changing needs and opportunities. Incorporate plans for sustainability of the investment, including through grants and service provision.

- Meet delivery milestones and to sign up to the Digital Innovation Hub Programme Principles for Participation – this includes the FAIR data principles (Findable, Accessible, Interoperable and Reusable).

The purpose of the Hub is not to perform original research. The funding available to applicants will be to create "data as an infrastructure" that improves access to and quality of data and increases the UK's future research and innovation capability. While Hubs will support research and innovation activities through the creation of new data and services they provide, the funding from this call will not support specific research projects. Research activities will be funded initially through the wider APDP initiative and through other routes in the longer-term.

THANK YOU!

IF YOU HAVE ANY FURTHER QUESTIONS REGARDING THE APDP PAIN RESEARCH DATA HUB, PLEASE CONTACT SPFPAIN@MRC.UKRI.ORG