Pharmacogenomics and asthma treatment: acceptability to children, families and healthcare professionals

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## Abstract word count: 249

## Word count: (excluding abstract and references): 2507

## Figures: 1

## Tables: 4

## Keywords: Asthma management, paediatrics, genetics

# Abstract

## Background

Evidence supporting personalised treatment for asthma based on an individual’s genetics is mounting. The views of children and young people (CYP), parents, and healthcare professionals (HCPs) about this evolution of clinical care are not known.

## Methods

A pilot prospective questionnaire-based study was undertaken of CYP with asthma, their parents, and HCPs at a secondary/tertiary children’s hospital in the UK.

## Results

Fifty-nine questionnaires were distributed and 50 returned (response rate 84.7%), comprising 26 CYP (10 were 5-11 years, 11 were 12-15 years, and five were 16-18 years old), 13 parents and 11 HCPs. For all types of data, personal information was ranked as the “most important” (n=19, 47.5%) and “most private” (n=16, 40%), but with considerable variation across groups. Within health data, allergies were rated as “most important” (n=12, 30.8%), and mental health records the “most private” (n=21, 53.8%), again with variation across groups. A “personalised genetic asthma plan” was acceptable to the majority overall (n=40, 80.0%). With regard to sharing a CYP’s genetic data, 23 (46%) of participants were happy for unconditional sharing between HCPs, and 23 (46%) agreed to sharing solely in relation to the CYPs asthma management. Forty-two (84.0%) of participants felt CYP should be informed about genetic data being shared, and the majority felt this should commence by 12 years of age.

## Conclusion

The use of genetic information to guide management of asthma in CYP is largely acceptable to CYP, parents/guardians and HCPs. However, there are key differences between the opinions of CYP, parents, and HCPs.

# Introduction

Asthma is one of the most common chronic diseases of childhood, affecting one in 11 children in the UK and millions more worldwide, contributing to considerable burden on global healthcare systems (1, 2). The management of asthma is guided by evidence based guidelines (3, 4). Despite this, considerable variation in outcomes for children and young people (CYP) remains. At an individual patient level, there is known inter-individual variability in treatment response (5-7). Most cases of asthma in children are mild, but severe disease occurs, and sadly, 15-20 CYP die from asthma annually in the UK (8).

Genetics plays an important role in treatment responses in asthma (9-11), with pharmacogenomic studies identifying polymorphisms that alter either drug efficacy or increase the risk of adverse drug reactions (12, 13). While genomic data are not yet included in any of the national or international guidance (3, 4), there are polymorphisms approaching the levels of evidence required (12). Paediatrics has already successfully integrated genomic data into patient management and treatment for some conditions (14-19) but asthma is different to these existing examples: it is a common disease, affecting hundreds of thousands (1); multiple HCPs will coordinate care (20); and a range of therapies are available, each of which may require personalised assessment of risk and benefit.

Despite over 50 pharmacogenomic studies undertaken in CYP with asthma worldwide there are no published data on the views of CYP themselves, their parents/legal guardians, or HCPs, on the acceptability of using genetic information to guide treatment, and the factors influencing these decisions (21-23). Lessons learnt from the UK National Health Service (NHS) England care.data programme, launched in 2013, show that in attempting to centralize and share patient health and social care data, it is important to ensure clear two-way communications with the public, to ensure patient satisfaction and also safety of an individual’s data (24, 25).

The aim of this study was therefore to establish the views of CYP, parents/guardians and HCPs on the acceptability of genetic testing to guide the management of childhood asthma.

# Methods

## Study design and setting

A pilot prospective questionnaire-based study of CYP with asthma and their parents in either inpatient or outpatient settings, or HCPs working with CYP with asthma at a secondary and tertiary children’s hospital in the UK. Questionnaires provided to CYP were age-appropriate. The study recruited from October 2019 to January 2021. The full questionnaires are shown in the supplementary data section.

## Inclusion criteria

Three groups of people were eligible. (1) CYP aged 5-18 years with a diagnosis of asthma attending Alder Hey Children’s Hospital, (2) parent/guardian of a child with a diagnosis of asthma who attended Alder Hey Children’s Hospital and (3) HCPs providing care to children with asthma.

## Exclusion criteria

**CYP**

* Age >18 years
* Participant and parent/guardian were unable to read and/or understand the study information sheet

**Parent(s)/guardian(s)**

* Are a HCP
* Parent/guardian unable or unwilling to give consent (if participant aged 16 or under)

## Data handling and statistical analysis

All study data were compiled in a Microsoft Excel™ spreadsheet and stored securely as per protocol and General Data Protection Regulation). Simple, descriptive statistics were used to describe the data.

## Ethics approval

Granted by North West – Greater Manchester (GM) Central Health Research Authority, REC Reference no: 19/NW/0327.

Written, informed consent was obtained from patients aged 16 years or over, the parent or legal guardian of all participants aged <16 years, and HCPs. Written assent was obtained from those aged <16 years who understood the age appropriate patient information leaflet.

# Results

## Participants

Fifty-nine questionnaires were administered with a response rate of 84.7% (n=50). Participants comprised 26 CYP, 13 parents, and 11 HCPs. The HCP group was comprised of doctors (n=6), nurses (n=3), pharmacist (n=1) and one respiratory physiologist. A full breakdown is shown in the supplementary data section (Table S1).

## CYP and their asthma

The majority of questionnaires were completed about CYP whose asthma was diagnosed under the age of 5 years (n= 24, 61.5%), with the remainder receiving their diagnosis at 5-10 years (n=14, 35.9%) and 11-15 years (n=1, 2.6%). CYP and parents reported a median of 4.5 days school absence (range 0-50 days), in the previous 6 months. CYP age ≥12 years and parents were asked about emergency treatment of asthma in the previous 6 months: 23 (79.3%) participants (or their child) required emergency treatment; 20 (69.0%) received at least one course of oral steroids (median 1, range 0-10 courses); nine (31.0%) required hospital admission.

## About CYP’s data

All participants aged ≥12 years were asked to state which data, from a list of eight options, about a CYP was most important to them and which source they would most like to keep private (Table 1). The majority of parents and older CYP (n=18, 62.1%) felt that personal information (e.g. date of birth, address) was the most important data concerning CYP, while HCPs prioritised health data (n=10, 90.9%). Data considered “most private” varied across groups (Table 1). Overall, personal information (e.g. date of birth, address) was the most commonly selected, accounting for 40% (n=16) of responses.

All participants aged ≥12 years ranked health-related data in order of importance and privacy (Table 2) from a choice of seven options. Only questionnaires without multiple nominations for first place were included (one questionnaire from the parent group was excluded). There was considerable variation in what the different groups prioritised in terms of importance, but the most commonly prioritised response in all groups for privacy was mental health. A CYP’s unique genetic information did not feature highly in either importance or privacy for all groups.

## Genetic testing for health purposes

All participant groups were asked about genetic testing for health purposes. Thirty-four (68.0%) participants were familiar with the concept of genetic testing in healthcare; this included 12 CYP and all 11 HCPs. Of the CYP, only two of those in the 5-11 year group were familiar with the idea of genetic testing. The majority of participants (68.0 %) stated they had some knowledge of genetic testing but not very much. This figure will be biased in favour of HCPs. Supported by written information from the patient information leaflet and verbal information from the study investigators, participants were asked how acceptable they felt it would be to use a CYP’s genetic information to help guide their asthma management plan and develop a “personalised genetic asthma plan.” Across all participants, 40 (80.0%) agreed it would be acceptable and most felt that all HCPs involved in managing a CYP’s asthma (including general practitioners, asthma consultants and asthma specialist nurses) should be involved in the decision to develop such a plan. One participant in the 12-15 year age group suggested that parents should also be involved in this decision.

Older CYP (>12 years), parents and HCPs were asked about when CYP should be offered genetic testing for their asthma. Twelve (30.0%) felt CYP should be tested when first diagnosed; 24 (60.0%) felt all CYP with asthma should be tested as soon as possible and one (2.5%) felt only new patients should be offered testing. One (2.5%) HCP felt we should not be offering genetic testing to CYP and one parent (2.5%) did not respond.

With regard to how the results of genetic test should be relayed to CYP and their families, HCPs, parents and 16-18 year olds showed a stronger preference towards communication in person (Table 3). Those in the 12-15 year age group, were more willing to accept alternative forms of communication including post, email and telephone (Table 3).

All CYP were asked to whom they felt results of genetic testing should be communicated. All age groups showed a very strong preference to both parents and the CYP receiving the results (21/26, 80.8%). Only one CYP (3.8%) in the 16-18 year group felt the results should only be communicated directly to the CYP.

Participants were shown two examples of genetic reports, one from a NHS source and one from a commercial company (23andMe™), as examples of how genetic testing results are currently presented. Participants were asked to state their preference and invited to make any comments on their content and design. Seventeen (42.5%) preferred the NHS example; 15 (37.5%) the commercial example and four (10.0%) showed no preference for either. HCPs favoured the commercial report (7/11, 63.6%) but two HCPs commented that both examples were quite technical and members of the public may struggle to understand the information contained in the reports. A Flesch reading ease score of 34.2 and 34.9 for the NHS sourced and commercial report respectively makes both of these documents “difficult” to read, requiring a UK higher education to adequately understand (26).

The final question in this section asked participants to state how much information they would prefer to receive on a CYP’s suitability for a personalised genetic asthma plan. Only 5 (12.5%) preferred to receive a basic yes or no answer. Sixteen (40.0%) wished to receive more detailed information if the CYP’s genetic data would affect their asthma treatment plan and 17 (42.5%) stated they would like to receive all detailed information regardless of the result; this last option was not felt suitable by any of the HCP participants.

## Sharing of genetic data

The final section of the questionnaire was designed to obtain participant views on the sharing of genetic data. All individuals were asked whether they would be happy for HCPs to share the CYP’s genetic information with other HCPs involved in the care of the CYP. Twenty-three (46.0%) of participants were happy to share data between HCPs with no added stipulations. An additional 23 (46.0%) participants stated they would be happy to share the data but only when necessary to help manage a CYP’s asthma; a view particularly shared by HCPs. Two parents (4.0%) and two CYP (4.0%) were not happy to share genetic information.

Participants were asked if CYP should be informed beforehand if it was necessary to share their genetic data. Forty-two (84.0%) of participants felt CYP should be informed. Additionally, participants were requested to decide at what age CYP should be asked (Figure 1). One HCP commented that this conversation would depend on the CYP’s co-morbidities and level of understanding.

Depending on the form of genetic test used, data obtained can sometimes be relevant to more than one disease and therefore in some situations it may be necessary for HCPs managing a CYP’s asthma to share this information with other clinical teams. All participants were informed of this (see questionnaires in supplementary data section) and asked to state when/if this would be an acceptable course of action (Table 4). The majority of non-HCP participants (66.3%) were happy to share information without restraint, however HCPs felt CYP and their family should always give permission beforehand.

Participants were then asked who should have access to the genetic data used to guide a CYP’s asthma treatment. Multiple answers were accepted. These data are summarised in Table 4. For the majority of professionals listed, participants were happy for them to have access to the CYP’s genetic data. No participants felt that none should have access and one participant suggested that the CYP’s family be included in the list of professional groups.

After specifically highlighting to the respondents that genetic information can sometimes reveal unexpected information about members of the family (in an age-appropriate way), the final question for all participants was to state whether they now had any concerns about the sharing of genetic data, and to describe any concerns in free text form. Thirty participants (60.0%), including 19 CYP, six parents and five HCPs stated they had no concerns and would still be happy to share their genetic data; 18 (36.0%) now had some concerns and would want further information before sharing and only one participant aged 12-15 years (2.0%) had concerns such that they would not want their genetic data shared. Concerns raised included the possibility of CYP discovering they were adopted, non-paternity and data security.

# Discussion

This is the first study to establish the views of CYP, parents/guardians, and HCPs on the acceptability of genetic testing to guide management of childhood asthma. This pilot study has highlighted that CYP provide carefully considered responses to these complex questions, with considerable differences between both the views of CYP, parents, and HCPs, but also between CYP of different ages. As interest in the use of genetic data to help guide paediatric asthma management increases (27), it is important to ensure that CYP of all ages, as well as parents and HCPs, are involved in the planning of these services to maximise the chance of successful implementation.

This cohort, in line with the literature and national data, reported significant impact of asthma on their lives (28, 29). However, neither ethnicity nor income data were collected, and this work was undertaken in a single centre. A much greater patient and public involvement and engagement strategy with larger cohorts with representative data from a range of locations, ethnic and socio-economic groups will be required to inform broader clinical implementation.

Although this was a small pilot study with unbalanced groups, and therefore carries the risk of bias, it was particularly noteworthy that CYP across ages prioritised different sources of personal data in terms of both importance and need for maintaining privacy, and surprisingly genetic information did not score particularly highly, in terms of importance or privacy for any group. To avoid unforeseen consequences of sharing of data of this kind, additional work with CYP and parents may be required to ensure this reflects their opinions based on complete understanding. The majority felt it was acceptable to use genetic data to guide CYP’s asthma treatment in the form of a personalised genetic asthma plan, and participants were also happy for genetic information to be shared amongst HCPs, if the information was relevant to their asthma management. Whilst this is reassuring for future service planning, cautions were expressed in terms of data sharing between HCPs and family members for incidental findings.

Asides from the small sample group, one of the main limitations of this study is the lack of familiarity of genetic testing in non-HCP participants. Whilst questions from participants were clarified by the study investigator, it is possible that some participants provided answers to subsequent questions on the use of genetics for health care purposes without a full appreciation of what personalised genetics embodies.

While pharmacogenomic testing is currently used in some rare paediatric diseases, current national and international guidelines for asthma do not recommend it [REF]. Despite the number of studies carried out, there have been contradictory results, the endpoints have not been well aligned to the established CORE outcome set for childhood asthma, and there has been disproportionate focus on efficacy (rather than adverse effects) [REF]. Despite all this, international consortia have coalesced [REF] and through rigorous meta-analysis of studies, there is now evidence supporting pilot pharmacogenomics testing of 4 or more drug-gene pairs [REF]. While this change in management may take several years to be established in practice, now is the time for studies to ensure the views of CYP and families

Leading governing bodies for genetics recommend that genetic results are communicated in a clear manner (including to non-specialists and specialists alike), yet practical guidance is minimal, and guidance for children non-existent (31-33). Farmer *et al.* (34) produced a reporting template based on a series of semi-structured interviews, with adult participants, which contained all the major elements important to patients, clinicians and specialist who receive them. Similar efforts will be required for CYP.

# Conclusion

The use of genetic information to guide management of asthma in CYP is largely acceptable to CYP, parents/guardians and HCPs. However, there are key differences between their opinions.

# Key Messages

**What is known about this topic?**

There are no published data on the views of CYP, parents/legal guardians or their HCPs on the acceptability of using genetic information to guide asthma management.

**What this study adds?**

* The use of genetic information to guide management of asthma in CYP is largely acceptable to CYP, parents/guardians and HCPs.
* Children, young people, and their parents have distinct views about handling of pharmacogenomic data that differentiate them from both each other, and from healthcare professionals.
* Understanding these opinions is crucial to developing and implementing successful pharmacogenomic services in the UK.

## Competing interests

The study was funded by the MRC Confidence in Concept scheme.

## Contributor statement

CP monitored data collection for the whole study, cleaned and analysed the data, and drafted and revised the paper. LB and CK designed data collection tools. GS, NR, LB and CK implemented the study. IS, MP and DBH contributed to the grant application and study design. DBH initiated the study, monitored data collection for the whole study, and revised the draft paper.

## Acknowledgements

This is a summary of independent research funded by MRC and carried out at the National Institute for Health Research (NIHR) Alder Hey Clinical Research Facility. The views expressed are those of the author(s) and not necessarily those of the MRC, NHS, the NIHR or the Department of Health.

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# **Tables and Figures**

**Table 1. Most importance sources of data concerning CYP (bold responses are the most common for each group)**

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Data source** | **Which data source is most IMPORTANT,**  **n (relative frequency, %)** | | | | | **Which data source is most PRIVATE,**  **n (relative frequency, %)** | | | | |
| **12-15 years**  **(n = 11)** | **16-18 years**  **(n = 5)** | **Parents**  **(n = 13)** | **HCP**  **(n = 11)** | **All participants (n = 40)** | **12-15 years**  **(n = 11)** | **16-18 years**  **(n = 5)** | **Parents**  **(n = 13)** | **HCP**  **(n = 11)** | **All participants**  **(n = 40)** |
| Personal Information | **5 (45.5)** | **2 (40.0)** | **11 (84.6)** | 1 (9.1) | **19 (47.5)** | 3 (27.3) | 0 (0) | **9 (69.2)** | 4 (36.4) | **16 (40.0)** |
| Social media & internet | 3 (27.3) | 1 (20.0) | 1 (7.7) | 0 (0) | 5 (12.5) | 1 (9.1) | 1 (20.0) | 3 (23.1) | 0 (0) | 5 (12.5) |
| Educational information | 1 (9.1) | 0 (0) | 0 (0) | 0 (0) | 1 (2.5) | 1 (9.1) | **2 (40.0)** | 0 (0) | 0 (0) | 3 (7.5) |
| Shopping habits | 0 (0) | 0 (0) | 0 (0) | 0 (0) | 0 (0) | 0 (0) | 0 (0) | 0 (0) | 0 (0) | 0 (0) |
| Health | 2 (18.2) | 1 (20.0) | 1 (7.7) | **10 (90.9)** | 14 (35.0) | **4 (36.4)** | 0 (0) | 0 (0) | **6 (54.5)** | 10 (25.0) |
| Photographs & videos | 0 (0) | 1 (20.0) | 0 (0) | 0 (0) | 1 (2.5) | 1 (9.1) | **2 (40.0)** | 1 (7.7) | 1 (9.1) | 5 (12.5) |
| Lifestyle information | 0 (0) | 0 (0) | 0 (0) | 0 (0) | 0 (0) | 1 (9.1) | 0 (0) | 0 (0) | 0 (0) | 1 (2.5) |

**Table 2. Ranked importance of health data**

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Health data** | **Which HEALTH data source is most IMPORTANT,**  **n (relative frequency, %)** | | | | | **Which HEALTH data source should be most PRIVATE,**  **n (relative frequency, %)** | | | | |
| **12-15 years**  **(n = 11)** | **16-18 years**  **(n = 5)** | **Parents**  **(n = 12)** | **HCP**  **(n = 11)** | **All participants (n = 39)** | **12-15 years**  **(n = 11)** | **16-18 years**  **(n = 5)** | **Parents**  **(n = 12)** | **HCP**  **(n = 11)** | **All participants (n = 39)** |
| Unique genetic information | 1 (9.1) | 1 (20.0) | 2 (16.7) | 0 (0) | 4 (10.3) | 2 (18.2) | 0 (0) | 3 (25.0) | 2 (18.2) | 7 (17.9) |
| Mental health records | 3 (27.3) | **2 (40.0)** | 1 (8.3) | 2 (18.2) | 8 (20.5) | **6 (54.5)** | **3 (60.0)** | **4 (33.3)** | **8 (72.7)** | **21 (53.8)** |
| Physical health records | 1 (9.1) | 1 (20.0) | 1 (8.3) | **4 (36.4)** | 7 (17.9) | 2 (18.2) | 1 (20.0) | 2 (16.7) | 0 (0) | 5 (12.8) |
| Medications used | 0 (0) | 0 (0) | **5 (41.7)** | 1 (9.1) | 6 (15.4) | 0 (0) | 0 (0) | 1 (8.3) | 0 (0) | 1 (2.6) |
| Medical tests undertaken | 1 (9.1) | 0 (0) | 0 (0) | 1 (9.1) | 2 (5.1) | 1 (9.1) | 0 (0) | 2 (16.7) | 1 (9.1) | 4 (10.3) |
| Doctors seen | 0 (0) | 0 (0) | 0 (0) | 0 (0) | 0 (0) | 0 (0) | 0 (0) | 0 (0) | 0 (0) | 0 (0) |
| Allergies | **5 (45.5)** | 1 (20.0) | 3 (25.0) | 3 (27.3) | **12 (30.8)** | 0 (0) | 1 (20.0) | 0 (0) | 0 (0) | 1 (2.6) |

**Table 3. Preferred method of receiving results on genetic testing**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Method of communication** | **Participant group, n (relative frequency, %)** | | | |
| **12-15 years** | **16-18 years** | **Parents** | **HCP** |
| In person | **4 (36.4)** | **4 (80.0)** | **7 (46.7)** | **10 (90.9)** |
| Post | 3 (27.3) | 1 (20.0) | **7 (46.7)** | 1 (9.1) |
| Telephone | 2 (18.2) | 0 (0) | 1 (6.7) | 0 (0) |
| Email | 1 (9.1) | 0 (0) | 0 (0) | 0 (0) |
| Not known | 1 (9.1) | 0 (0) | 0 (0) | 0 (0) |

**Table 4. Views on the sharing and accessibility of genetic data from CYP with asthma (bold response the most common answer)**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Response** | **Sharing of genetic data with other clinical teams, n (relative frequency, %)** | | | | |
| **5-11 years** | **12-15 years** | **16-18 years** | **Parents** | **HCP** |
| Always | **6 (60.0)** | **7 (63.6)** | **4 (80.0)** | **8 (61.5)** | 1 (9.1) |
| When worried | 1 (10.0) | 1 (9.1) | 1 (20.0) | 3 (23.1) | 0 (0) |
| After asking permission | 3 (30.0) | 2 (18.2) | 0 (0) | 2 (15.4) | **10 (90.9)** |
| Never | 0 (0) | 0 (0) | 0 (0) | 0 (0) | 0 (0) |
| Not known | 0 (0) | 1 (9.1) | 0 (0) | 0 (0) | 0 (0) |
| **Professional group** | **Accessibility of genetic data to other professionals, n (relative frequency, %)** | | | | |
| **5-11 years** | **12-15 years** | **16-18 years** | **Parents** | **HCP** |
| Hospital team | **6 (60.0)** | **5 (45.5)** | **2 (40.0)** | **8 (61.5)** | **11 (100.0)** |
| GP | **6 (60.0)** | **5 (45.5)** | 1 (20.0) | 7 (53.8) | 8 (72.7) |
| Primary care nurse | **6 (60.0)** | 2 (18.2) | 0 (0) | 5 (38.5) | 7 (63.6) |
| School nurse | 5 (50.0) | 2 (18.2) | 0 (0) | 1 (7.7) | 2 (18.2) |
| All of the above | 4 (40.0) | 3 (27.3) | **2 (40.0)** | 7 (53.8) | 1 (9.1) |
| Anyone involved in care of CYP | **6 (60.0)** | **5 (45.5)** | 1 (20.0) | 4 (30.1) | 4 (36.3) |
| Other | 0 (0) | 1 (9.1) | 0 (0) | 0 (0) | 0 (0) |
| None | 0 (0) | 0 (0) | 0 (0) | 0 (0) | 0 (0) |

**Figure 1.** Age at which participants felt CYP should be asked whether they agree to sharing of genetic data. *Permissions to re-use the figure can be obtained from the corresponding author.*