

FindMyLipidClinic.com: A global Directory of lipid clinics and patient organisations to improve dyslipidemia care

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ABSTRACT

Keywords

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Information available on lipid clinics and patient support and advocacy groups, such as location and services provided, is limited or unknown to patients with dyslipidemia and their family members who may also be affected, and non-specialist clinicians, hindering accessibility to appropriate healthcare. To overcome this, the European Atherosclerosis Society Familial Hypercholesterolemia Study Collaboration (EAS FHSC) led by Imperial College London has, in collaboration with the European FH Patient Network (FH Europe), developed FindMyLipidClinic.com, a global Directory of lipid clinics and patient support groups in 29 common languages. Since its launch in 2020, around 4,000 visitors have conducted 12,000 searches across 1,100 locations, which may have retrieved up to 124 lipid clinics and 29 patient groups currently listed in 39 and 27 countries, respectively. However, clinics and patient organisations not currently listed are encouraged to join this directory, and it would also benefit further from collaborations with other existing directories able to contribute.

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Introduction

Lipoprotein metabolism disorders, dyslipidemia, are widely established as a major risk factor for cardiovascular disease (1, 2), yet they are often diagnosed and treated late, and therefore management of these conditions is frequently suboptimal. For example, familial hypercholesterolemia (FH), the most common autosomal dominant condition, characterised by high levels of low-density lipoprotein cholesterol in blood, has an estimated prevalence of 1:311 worldwide (3) and is often diagnosed late, on average at age 44 years (4). FH patients are often identified by opportunistic screening, rather than by the more cost-effective cascade testing of family members (5). Moreover, once they are diagnosed, less than 3% of FH patients on lipid-lowering therapy achieve the acceptable cholesterol targets recommended by clinical guidelines (4). It is likely that such inade-

quacies of care are partly attributable to a lack of information available on specialist care and lipid clinics to non-specialist clinicians and patients, for referrals for appropriate diagnosis and treatment.

The difficulty in locating specialist lipid clinics in the absence of a global directory may lead to inequalities in the management of patients with dyslipidemia, as well-informed practitioners may be better equipped to refer patients to the necessary care. Furthermore, this can lead to more collaborative and shared decision making as healthcare delivery moves towards person-centred care. Patient advocacy groups, such as FH Europe, the European FH Patient Network (fheurope.org), aim to raise awareness of dyslipidemia among patients, their relatives, policymakers, and clinicians (6, 7), and could potentially reduce these inequalities by guiding patients and non-specialist clinicians toward appropriate specialists. To our knowledge, the few lipid clinic directories available were limited to the Family Heart

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Foundation in the United States (8), the Fundación Hipercolesterolemia Familiar in Spain (9) and the European Atherosclerosis Society [EAS] (10). However, these initiatives are limited by geography and information provided, which restricts their utilities. Inherited dyslipidemias know no borders and the relatives of newly diagnosed patients, who may also potentially be affected by the disease, may reside in different regions not covered by these directories. Ability to filter clinics by services provided to children and/or adults is also lacking in all these initiatives despite being instrumental to identifying clinics able to implement more sophisticated screening programs such as the combination of universal early childhood screening and reverse cascade testing of adults relatives advocated by FH Europe.

Methods

Recently, Imperial College London has launched FindMyLipidClinic.com an online global directory of both lipid clinics and patient support groups drawn from the resources of the EAS Familial Hypercholesterolemia Study Collaboration (FHSC) and FH Europe, respectively. FindMyLipidClinic.com uses advanced mapping techniques to connect patients, their relatives and non-specialist clinicians with specialist clinicians and/or patient support groups so patients may receive the care they need to manage dyslipidemia in convenient locations (Figure 1).

FindMyLipidClinic.com is available in 29 languages increasing

worldwide accessibility. The web application embeds innovative “Bing Maps” search and mapping functionalities that have kindly been made available to Imperial College London by Microsoft through a non-profit licence (Figure 1). FindMyLipidClinic.com also enable its users to filter specialist clinics according to the services offered to adults and children patients, which include but are not limited to cascade testing, genetic testing, genetic counselling, lipoprotein(a) [Lp(a)] testing, imaging, nutritional advice, and lipoprotein apheresis (Table 1). Patient support groups generally provide free services to patients including but not limited to sharing of information on diagnosis and management of their condition via webinars, helplines, and information leaflets. However, FindMyLipidClinic.com does not allow its users to filter patient support groups based on these services.

FindMyLipidClinic.com is a non-commercial initiative that is committed to respecting the privacy of its users. As a result, the web application does not store any personal information of its users and is compliant with the European General Data Protection Regulation (GDPR).

Results

FindMyLipidClinic.com is growing rapidly and currently contains 124 specialist lipid clinics across 39 countries most of which are part of the EAS FHSC global network of dyslipidemias specialists, and 29 patient advocacy groups across 27 countries mostly contributed by

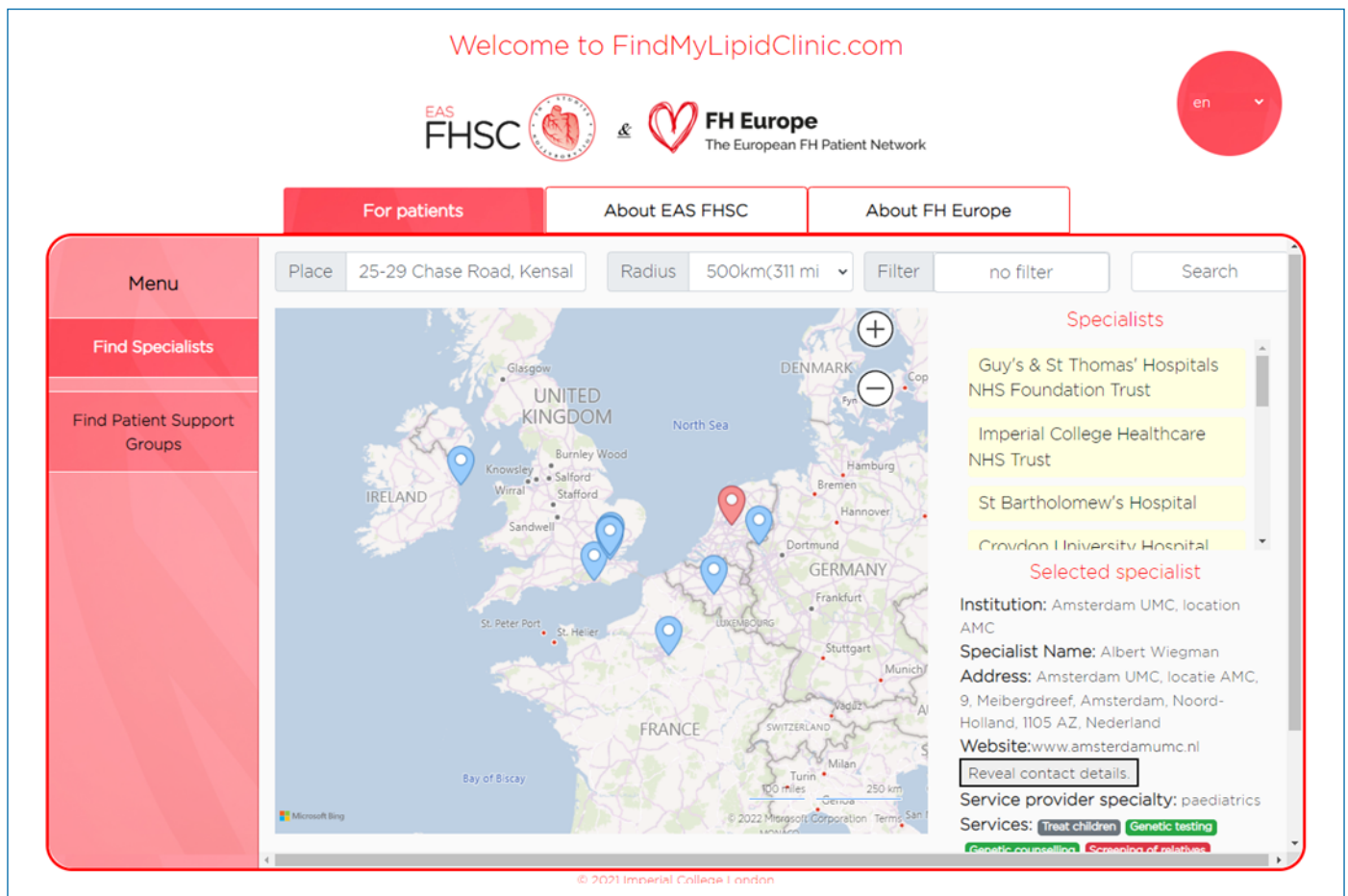


Figure 1 | Screenshot of FindMyLipidClinic.com’s main page that allows its users to search for and filter clinics and to view the detailed information of a selected clinic.

Table 1 | Characteristics of clinics listed on FindMyLipidClinics.com.

Clinics Characteristics	Count and Proportion <i>n</i> (%)
Patients Treated	
Adults	108 (87%)
Children	58 (47%)
Screening, Testing & Counselling	
Cascade Screening	109 (88%)
Lp(a) Testing	88 (71%)
Genetic Testing	70 (56%)
Genetic Counselling	67 (54%)
Imaging	
Ultrasound	102 (82%)
Echography	97 (78%)
Computed Tomography (CT) scan	72 (58%)
Angiography	64 (52%)
Magnetic Resonance Imaging (MRI)	62 (50%)
Imaging	
Dietitian advice	75 (60%)
Apheresis on site	39 (31%)
Apheresis on referral	33 (27%)

The European FH Patient Network (FH Europe). The map in **Figure 2** shows the location of the clinics listed in the worldwide directory as well as countries where at least one known patient organisation is listed to date.

Over the last 18 months, 4,000 unique visitors of this directory have searched for lipid clinics and patient advocacy groups ~12,000 times across over 1,100 unique locations. Due to the infancy of this ongoing project many countries do not yet have either a lipid clinic or patient support group listed, even in areas such as the United States of America, Canada, Mexico, Australia where the number of potential users appears to be high (**Figure 2**).

Discussion

FindMyLipidClinic.com and other similar directories rely on a high volume of listings across as many world regions as possible to successfully guide patients to the specialist care required to manage their condition. Lipid specialists and patient organisations that are not already listed are therefore encouraged to list their clinics on FindMyLipidClinic.com. Similarly, administrators of other directories are invited to collaborate, where possible, by referring their listed clinics and patient organisations to our global directory. The simple steps outlined on <https://findmylipidclinic.com/#/clinician-interface/listmyclinic> describe how to take part in this initiative. Information/data about publicly available lipid clinics and patient support organisations on FindMyLipidClinic.com is legally limited to use via the website only and may not be shared otherwise.

Ongoing dissemination of this initiative relies on a Google Ad Grant campaign that displays the link to FindMyLipidClinic.com to users searching for dyslipidemia-related terms such as ‘hypercholesterolemia’, ‘lipid’ and ‘lp(a)’ and their combinations. Unfortunately the Google algorithm determines when the link is displayed to Google users and depends on many factors out of our control. The campaign is active in 29 languages and has no geographical limits. Yet, dissemination through Google alone is far from enough and we call

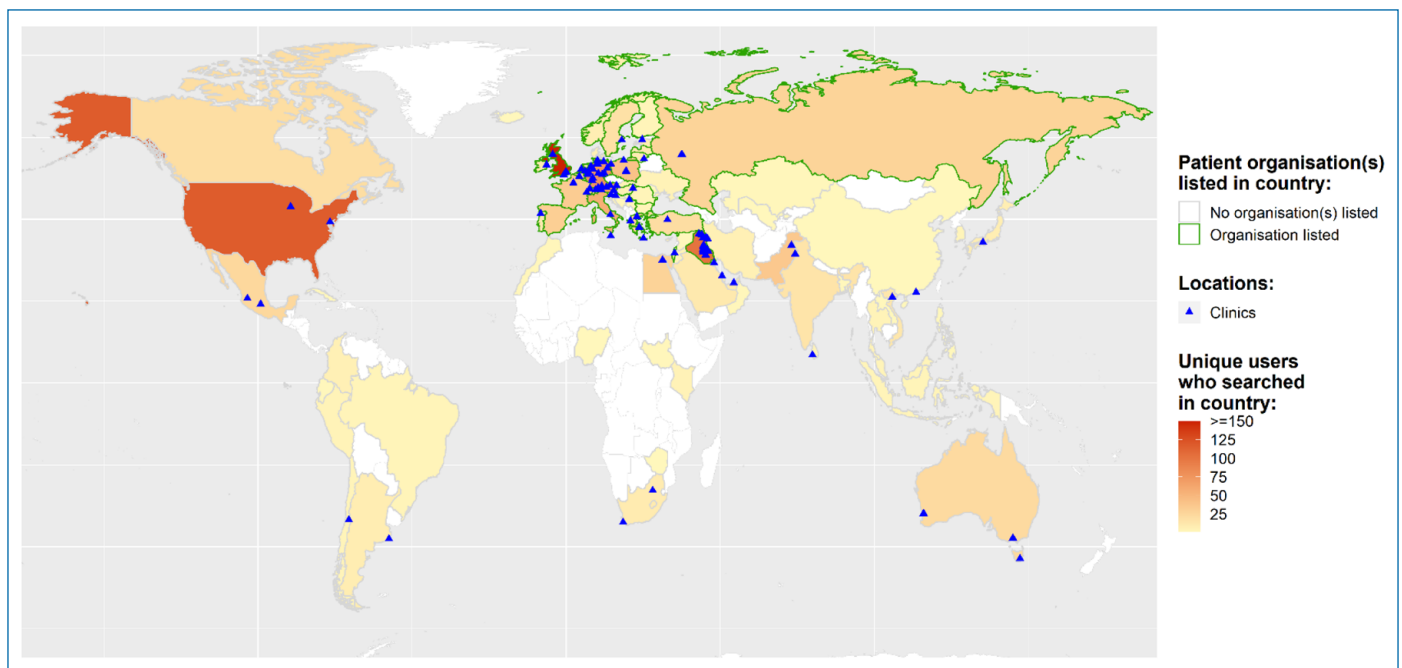


Figure 2 | Location of clinics and patient organisations listed on FindMyLipidClinic.com and number of searches by country.

on readers to disseminate the initiative within their network using their preferred means (e.g. social media, emails, meetings, and presentations).

FindMyLipidClinic.com has a number of practical applications which may include: (i) helping patients and non-specialist clinicians to find specialist clinicians who can diagnose and treat dyslipidemia, (ii) help non-specialist clinicians to find their foreign colleagues who can treat relatives of patients with genetic dyslipidemia living in another country, and (iii) helping patients and their family members to seek advice from their closest patient support groups on how to better identify and live with a dyslipidemia. By freely enabling these practical applications to connect patients, their relatives, non-specialist, and specialist clinicians, FindMyLipidClinic.com can contribute to improvements in the identification and management of dyslipidemia worldwide, encourage shared decision-making between people and the services that provide care, and thus diminish the inequality gap between geopolitical and healthcare settings.

There is also an opportunity to understand the accessibility and availability of lipid services per population size and enable policy-makers to allocate resources accordingly. The success of this initiative however depends on adequate and unbiased coverage of patient populations by lipid clinics and patient support groups, both in terms of geographical spread and in the provision of adequate services to identify, treat and support these patients. All lipid clinics, patient advocacy groups and administrators of local directories are invited to list their organisations and/or to disseminate this global initiative within their respective networks.

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Conflict of interest

Christophe A.T. Stevens reports grants from Pfizer, Amgen, Merck Sharp & Dohme, Sanofi-Aventis, Daiichi Sankyo, and Regeneron all outside the submitted work.

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Kanika I. Dharmayat reports grants from Daiichi-Sankyo, Amgen and Regeneron, and personal fees from Bayer and Regeneron; all outside the submitted work.

Julia Brandts reports a grant from AstraZeneca; and has received speaker honoraria from Amgen; all outside of the submitted work.

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Authorship and Author Contributions

Christophe A.T. Stevens, Alexander R.M. Lyons, Magdalena Daccord, and Kausik K. Ray conceived and wrote the article. All authors contributed to the design of the FindMyLipidClinic.com Directory, critically revised the manuscript, and gave their final approval.

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