Title: Non-clinical sexual health support for HIV, viral hepatitis, and other sexually transmitted infections in gay, bisexual and other men who have sex with men: Protocol for a European Community Health Worker Online Survey (ECHOES)

Authors:

N Sherriff* - School of Health Sciences, and Centre for Transforming Sexuality & Gender, University of Brighton - Brighton, United Kingdom

J Huber - School of Health Sciences, University of Brighton - Brighton, United Kingdom

N McGlynn - School of Environment & Technology, University of Brighton - Brighton, United Kingdom

C Llewellyn - Brighton and Sussex Medical School, University of Sussex, Brighton, United Kingdom

A Pollard - Brighton and Sussex Medical School, University of Sussex, Brighton, United Kingdom

N Lorente - Centre d'Estudis Epidemiològics sobre les Infeccions de Transmissió Sexual i Sida de Catalunya (CEEISCAT) / Agència de Salut Pública de Catalunya, - Badalona, Spain; Institut Investigació Germans Trias i Pujol (IGTP), Badalona, Spain.

C Folch - Centre d'Estudis Epidemiològics sobre les Infeccions de Transmissió Sexual i Sida de Catalunya (CEEISCAT) / Agència de Salut Pública de Catalunya, - Badalona, Spain; CIBER Epidemiología y Salud Pública (CIBERESP), Madrid, Spain

C Cawley - Robert Koch Institute - Berlin, Germany

O Panochenko - Aids Action Europe - Berlin, Germany

M Krone - Aids Action Europe - Berlin, Germany

M Dutarte - European Aids Treatment Group - Brussels, Belgium

J Casabona - Centre d'Estudis Epidemiològics sobre les Infeccions de Transmissió Sexual i Sida de Catalunya (CEEISCAT) / Agència de Salut Pública de Catalunya, - Badalona, Spain; CIBER Epidemiología y Salud Pública (CIBERESP), Madrid, Spain

***Correspondence:** Professor Nigel Sherriff
School of Health Sciences
Centre for Transforming Sexuality & Gender
University of Brighton
Falmer, Brighton, BN1 9PH
Email: n.s.sherriff@brighton.ac.uk
Tel: +441273 64 4539

Title: Non-clinical sexual health support for HIV, viral hepatitis, and other sexually transmitted infections in gay, bisexual and other men who have sex with men: Protocol for a European Community Health Worker Online Survey (ECHOES)

Abstract

Background: The term Community Health Worker (CHW) can apply to a wide range of individuals providing health services and support for diverse populations. Very little is known about the role of CHWs in Europe who work in non-clinical settings and who promote sexual health and prevent HIV/STI among gay, bisexual and other men who have sex with men (MSM).

Objective: This paper describes the development and piloting of the first European Community Health Worker Online Survey (ECHOES) as part of the broader European Union (EU) funded ESTICOM project (European Surveys and Trainings to Improve MSM Community Health). The questionnaire aimed to assess the knowledge, attitudes, and practices of CHWs providing sexual health services to gay, bisexual and other MSM in European settings.

Methods and analysis: ECHOES comprises three superordinate domains divided into 10 subsections with 175 items (routed) based on a scoping exercise and literature review, online pre-piloting and a Europe-wide consultation. Additional piloting and cognitive debriefing interviews with stakeholders were conducted to identify comprehension issues and improve the clarity, intelligibility, accessibility, and acceptability of the survey. Psychometric properties including internal consistency of the standardised scales used as part of the survey including internal consistency were examined. The final survey was available to 33 countries in 16 languages.

Results: Recruitment closed on 31st January 2018. A total of 1,035 community health workers were available for analysis, after application of exclusion criteria.

Discussion: The findings of the survey will be available in late 2019 and will help characterise for the first time, the diverse role of CHWs who provide sexual health services to gay men, bisexual men and other MSM in Europe. Importantly, the data will be used to inform the content and design of a dedicated training programme for CHWs as part of the larger European Union (EU) funded ESTICOM project and provide recommendations for MSM-specific EU strategies to improve sexual health in general and to reduce HIV, viral hepatitis and other STIs incidence and prevalence in particular.

Key words: Community health worker, ECHOES, Europe, MSM, gay men, HIV, hepatitis, sexual health, sexually transmitted infections, peer support.

Introduction

Individuals who work in community-based settings have an important role to play in sexual health promotion and HIV/STI prevention amongst gay, bisexual, and other men who have sex with men (MSM) [(1)1-4]. In the United States [5-7] and elsewhere [8-10] such workers/volunteers are often characterised as Community Health Workers (CHWs); a workforce that has seemingly gained increased recognition, visibility, and legitimacy, and in the US at least, is now seen as an essential part of the public health system [11].

In a more global context, CHWs can be an important complement for under resourced health workforces, and can thus potentially be important in terms of increasing the availability of, and access to, health services [12-13]. Indeed, the evidence base regarding the positive contribution CHWs can make in the delivery of population-based health interventions is growing particularly in relation to child and maternal health, non-communicable diseases, and infectious diseases [14].

In the countries of the European Union (EU) and European Economic Area (EEA; which includes EU countries as well as Iceland, Liechtenstein and Norway), it is within this latter sphere (infectious diseases, and specifically HIV and other STIs) that the concept and role of CHWs has recently come to the fore. MSM continue to represent the predominant mode of HIV transmission in the EU/EEA accounting for 38% of all new HIV diagnoses in 2017 [15]. Although some countries have started to note a decline in HIV incidence amongst MSM (namely, Belgium, Greece, the Netherlands, Spain and the United Kingdom), overall rates of HIV diagnoses amongst MSM continue to increase.

The reasons for MSM being disproportionately affected by HIV and other STIs including viral hepatitis are complex and vary within the geographical and historical differences of the EU/EEA; factors include (but are not limited to), the complex interactions between sexual behaviours; sexually transmitted infections (STI); an increased biological vulnerability for HIV infections; social stigma associated with homosexuality; syndemics of mental health issues and substance (mis)use amongst MSM; structural, psychological and provider-associated barriers experienced by MSM when accessing sexual health services; a lack of data and research on MSM in many countries; a lack of funding for MSM targeted HIV/STI prevention and community based HIV testing; advances in communication technologies and their impact on partner seeking and sexual behaviour, and; high internal and cross-border mobility [e.g. 16].

Historically, and in addition to the above list, in many European countries the public health sector was slow in responding to the HIV epidemic (for example, due to conservative legislation around same-sex relationships, as well as cultural and socio-economic barriers fuelling stigma), leaving a void (*inter alia*) in prevention and advocacy activities and service development [16]. This void was filled out of necessity by gay

communities including non-governmental organisations (NGOs) particularly in Western Europe that proactively and progressively developed HIV prevention initiatives, programmes, and services targeted to the most affected key populations including MSM.

Unfortunately, such programmes and services have over the years been burdened by insecure funding streams (e.g. donations), poor linkage with formal health systems, lack of training and support for workers, fragmentation of purpose and roles, as well as competition for scarce resources with other actors and/or organisations. Together with a mixed and diverse nomenclature to characterise workers and/or volunteers (e.g. HIV prevention worker, outreach worker, sexual health worker, health promoter, peer counsellor, volunteer, health educator), this has arguably led to a somewhat fractured and unstable workforce. For instance, in Europe 'Community Health Worker' or 'CHW' as a term is rarely used and instead a plethora of disparate terms take its place [see for example 18-20], varying across organisations and countries. Such definitional uncertainties result in the precise nature of CHW work, practices, roles, knowledge, skills, and needs being poorly understood [3, 21].

In 2015 as part of the European Commission's Health Programme 2014-2020, the Consumers, Health, Agriculture and Food Executive Agency (CHAFEA) issued a tender specification providing an important opportunity to not only strengthen the community response to tackling HIV and other STIs amongst MSM, but to also raise awareness regarding the persisting legal, structural, political and social barriers hindering a more effective response to the syndemics of HIV, viral hepatitis B and C, and other STIs amongst MSM. The tender requested the development of a 'behavioural survey for HIV/AIDS and associated infections, and a survey and tailored training [programme] for community based health workers (CHWs) to facilitate access and improve the quality of prevention, diagnosis of HIV/AIDS, STI and viral hepatitis and health care services for MSM'. In this tender, the term CHW was introduced for the first time, as far as we are aware, to refer to the workforce in Europe that supports the sexual health needs of MSM around HIV, viral hepatitis, and other STIs.

This paper is based on the pan-European 3-year project entitled ESTICOM (European Surveys and Training to Improve MSM Community Health) that was funded via this CHAFEA tender (n° Chafea/2015/Health/38). ESTICOM (2016-2019) aims to develop: 1) A European online survey among MSM (European MSM Internet Survey - EMIS 2017); 2) A European online survey regarding the knowledge, attitudes, practices, and training needs of community health workers (CHW) who support MSM (ECHOES - the **E**uropean **C**ommunity **H**ealth Workers **O**nlin**E** **S**urvey), and; 3) A training programme for MSM-focused CHWs adaptable for all EU countries.

In this paper we present the protocol for the ECHOES survey as a core part of the larger ESTICOM project; an extensive questionnaire which grappled with definitional complexities of CHWs who support men who have sex with men. The overarching aim of the ECHOES survey was to gather data from community health workers helping to understand their role including their knowledge, attitudes, and practices; ultimately the information should aid the potential developments of the workforce by means of training and support, and policy development [22].

Methods

Design

A quantitative self-report questionnaire (ECHOES) was designed within the European Commission's funded ESTICOM project (www.esticom.eu). The questionnaire was administered online using the survey tool provided by the Demographix platform (www.demographix.com).

Aim and objectives

The overarching aim of the ECHOES study was to develop a multi-lingual Europe-wide online questionnaire capable of assessing the knowledge, attitudes, and practices of community-based health workers (CHW) providing sexual health services to gay, bisexual, and other MSM. Specifically research objectives were to: i) generate insight as to who CHWs in Europe are, what they do, where they do it, how, and why they do it; ii) identify barriers and challenges to CHWs activities; iii) identify skill/knowledge gaps and training needs, and iv) generate insights for the development of a dedicated training programme for CHWs as part of the larger ESTICOM project.

Study population

ECHOES is the first survey of its kind in Europe that addresses CHWs who provide sexual health support to gay, bisexual, and other MSM. Therefore, the CHW study population is mostly unknown to researchers, an issue which the ECHOES survey was, in part, designed to address. Thus, given the term CHW is not well known or used in Europe, a deliberately broad working definition was developed by the ECHOES development team for the purposes of defining the study population. Following an informal review of relevant literature, this working definition was achieved through a consensus-based process with Consortium partners drawing on elements of the nominal group technique (NGT). The NGT is essentially a group process involving problem identification, solution generation, and decision making. It can be particularly useful to ensure all parties are able to contribute and where the issue under question is controversial and/or the primary purpose is to come to clarification (rather than resolve differences of opinion). Thus, for ECHOES, a CHW was defined as: *"Someone who provides sexual health support around HIV/AIDS, viral hepatitis and*

other sexually transmitted infections (STIs), to gay, bisexual and other MSM. A CHW delivers health promotion or public health activities in community settings (not in a hospital or clinic)." [20] In other words according to our definition, a CHW can be any person working with MSM around sexual health support (paid or unpaid) with or without a medical (health) background as long as their work is conducted in community or non-clinical settings. Such a definition was intended to capture not only those whom are perhaps more traditionally associated with supporting MSM such as HIV outreach workers working in gay venues on behalf of non-governmental organisations, but all those whom may provide sexual health support in a variety of different sectors (e.g. educational, social care, housing, private sector etc.) and in diverse ways.

Detailed plans to engage with the target population and recruit to the survey were developed by the consortium partner AIDS Action Europe (AAE) in collaboration with study partners. AAE is a network of national networks, AIDS service organisations, and community-based groups which, at present, represents 415 NGOs in 47 countries in the WHO European Region. Briefly activities included an initial Europe-wide consultation exercise to generate insight on the most useful communication channels to reach CHWs with 44 responses being received from 32 countries (29 from countries eligible to be surveyed). Other strategies to recruit participants included direct (e)mailing (e.g. using translated email templates), website news items shared with pan-European HIV/AIDS organisations), paid social media promotion (Facebook), personal and professional contacts (e.g. via events such as the HIV/AIDS, TB and Hepatitis Civil Society Forum) interviews and case studies published online 'showcasing' the survey in specific countries, as well as a European webinar and marketing activities at relevant expert meetings and forums. ECHOES was also cross-promoted through a page delivered by the EMIS-2017 survey which was launched at the same. This page used the same screening questions as ECHOES to identify if EMIS responders were also CHWs and if so, to then direct respondents to the ECHOES survey. Full details of the recruitment strategy will be available in the report on findings expected to be available in late 2019 [23].

Inclusion and exclusion criteria

CHWs who satisfied the following criteria were eligible to participate in the survey if they:

a. Provided sexual health support for gay, bisexual and other MSM in a community setting (not in a hospital or clinic) during the last 12 months;
b. Provided support as a CHW in one of the 36 eligible countries (all 28 EU countries and neighbour countries: Bosnia Herzegovina, Iceland, Moldova, Norway, Russia, Serbia, Switzerland, and Ukraine);
c. Were aged 18 years or older;
d. Consented to take part in the survey.

Questionnaire development

The ECHOES survey was developed primarily by a Brighton-based study team of five academics (three psychologists specialising in MSM issues, behavioural medicine, survey design and sexual health/HIV [NS, JH, CL], a social geographer with expertise in sexual and gender identities [NMG], and a former CHW/researcher [AP]) in collaboration with colleagues from the wider ESTICOM project (particularly Objective Two partners; OP, MK, MD, NL, CF, JC).

Prior to the survey construction, a Europe-wide scoping exercise was conducted by the ESTICOM partners in order to review extant literature regarding the knowledge, attitudes and practices of CHWs concerning the sexual health of gay, bisexual and other MSM [24]. In addition, a more informal review was conducted by the ECHOES development team in order to develop a working definition of CHWs for European contexts, and to explore the existence of any CHW surveys in Europe or elsewhere. An additional aim of this extra review was to consult with project partners to share any available national or regional questionnaires targeting CHW in any language. No national or regional questionnaires targeting CHW were submitted to the ECHOES development team. The outcomes of both scoping reviews were broadly consistent in showing a lack of both peer reviewed and grey literature on CHWs involved in providing sexual health support aimed at gay, bisexual and other MSM in Europe.

In parallel to the scoping activities, an initial conceptual model of the survey was devised drawing on a consensus building exercise with project partners to collate their views as experts on a number of issues including: screening (who to include/exclude), the relative importance of different proposed areas of interest for the CHW survey (demographics, CHW activities/roles, settings, motivations, attitudes, knowledge, barriers, CHW development and support, training needs, and open text to propose any additional area), as well as estimates of the extent of data to be collected. Figure 1 shows the final conceptual model underlying the ECHOES survey, including all major components captured by the questionnaire. The conceptual underpinnings of the survey are informed broadly by ideas coming from the theory of planned behaviour [25-26] and other conceptual frameworks such as the health belief model [27] which suggest that action is strongly influenced by beliefs about benefits (and costs) of activities, and barriers and facilitators.

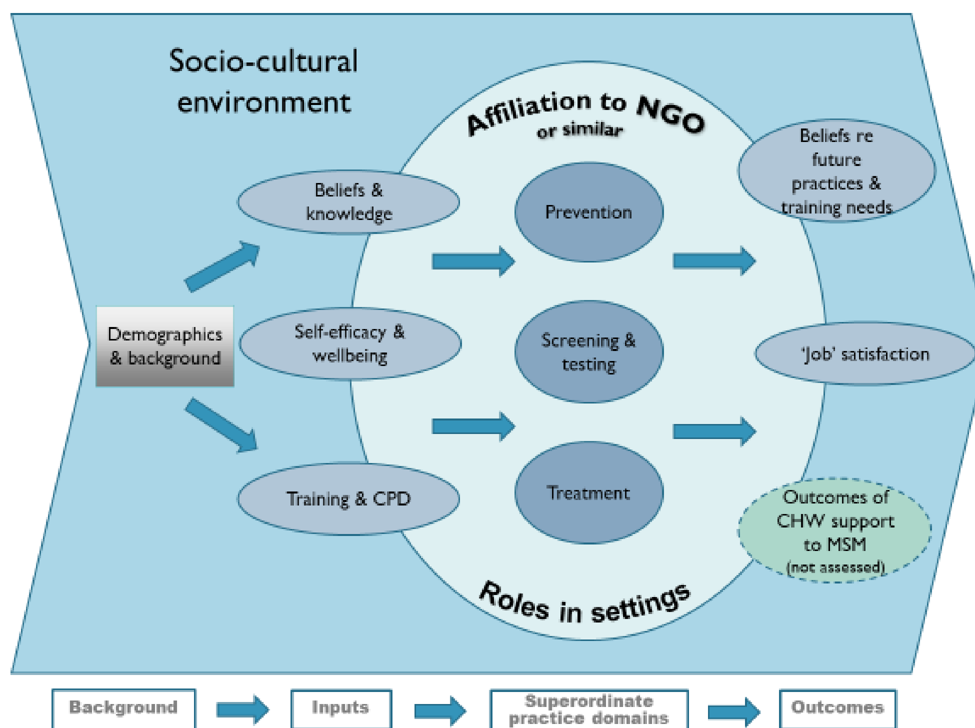

Figure 1. Diagram of ECHOES conceptual model

Based on the conceptual model, the questionnaire was structured around three superordinate practice domains around prevention, screening and testing, and treatment that form the core of the questionnaire (centre of the model). These practice domains are shaped by (i) affiliation to organisations (NGO or similar) and (ii) roles adopted in settings (e.g. peer supporter, clinician working as CHW within community). Demographics, background variables, cognitions (beliefs and knowledge on HIV and other STDs prevention, screening and treatment), person variables (self-efficacy and wellbeing), and prior training and CPD are inputs to and shape practices. Beliefs regarding future practices (e.g. providing POCT services) and training needs, job satisfaction and outcomes in MSM (not measured) reflect on and are a reflection of the activities carried out by CHWs ('practices'); for the purposes of the argument put forward in this paper they are considered to be Outcomes.

The ECHOES conceptual model will most likely aid analysis but should not be seen as capturing causal relationships. Based on our global or systems perspective and evidence available, links exist between many elements, influences are frequently bi-directional and probably recursive. The conceptual model will inform the statistical analysis but given the provisional and conceptual nature of this model, it will neither determine nor limit the analysis to e.g. links proposed by the model.

Piloting

Following the development of the conceptual model, a first full draft of the survey was developed on paper and online via demographix.com during early 2017. A pre-testing phase was initiated to make an initial assessment of this draft survey. Subsequent iterative rounds of small-scale online pre-piloting were undertaken during February-March 2017, both informally and internally at the University of Brighton, as well as externally with CHWs known to the research team. Approximately 25 individuals participated in this pre-testing phase, the purpose of which was to test out discrete sections of the questionnaire as they became available, checking for acceptability, completeness, comprehension, phrasing, and ease of use. As part of this process, respondents were asked to attempt to answer the draft sections followed by feedback to add/adapt/delete questions as necessary to make them relevant to the target sample.

Following completion of the series of online pre-tests, a broader consultation exercise was conducted utilising ESTICOM's wider networks. The draft ECHOES survey was sent out for its first consultation via MailChimp to 412 unique email addresses of ESTICOM subscribers during March-April 2017. Twenty-eight detailed responses were received from 18 countries representing 25 organisations including European agencies and national government departments as well as specialist Non-Governmental Organisations (NGOs) (e.g. in sexual health, HIV, and LGBTI issues), Checkpoints, Public Health agencies, other organisations. The consultation provided a very clear steer on modifying the ECHOES survey to develop it further for online piloting and finalisation. In responding to the outcomes of the consultation, every nomination for amendment (e.g. cut/add/change), comment, and criticism was considered by the ECHOES development team. Respondents identified typos and routing errors which were subsequently rectified. Discussion by the research team led to the de-selection, modification and the addition of numerous questions.

Following the pre-testing phase, a small number (n=7) of cognitive debrief interviews were conducted by one of the authors (NMG) with participants experienced in CHW work/volunteering or appropriate fields of sexual health; recruitment was opportunistic but heterogeneity was maximised. The aim of these interviews was to gather a rich evidence base to assess and improve the clarity, intelligibility, accessibility and acceptability of the online survey. Data generated from the interviews was used to further revise the online survey before the wider online piloting.

Following the cognitive debriefing interviews, final adjustments were made to the survey and transferred onto Demographix for the launch of a second pilot survey. The aims of the second pilot survey were to test the ECHOES survey in its most complete form, and to provide sufficient data for validity checking of particular

questions. Recruitment for the pilot test aimed for a sample size of 50 with a spread across European regions; however the pilot would be available in English only. The limited sample size was fixed in order not to exhaust the potential CHW population. The second pilot survey was opened for responses during 3 weeks in June 2017. An invitation to complete the pilot survey (see Appendix E) was emailed using MailChimp, and Consortium partners were also asked to circulate the invitation through their own relevant networks. Reminder emails were sent on 15th June and 19th June 2017. Fifty-four responses were received. Preliminary analysis of this pilot data demonstrated that the survey appeared to work well technically and could generate data that could answer the research objectives.

Final ECHOES questionnaire design/content

With reference to Figure 1, the ECHOES survey thus comprises 3 superordinate domains, with 175 questions (heavily routed), divided into 10 subsections (see Figure 2); up to 250 data points were collected for each respondent. Approximately 10% of all questions were drawn from three validated scales documenting well-being, self-efficacy, and job satisfaction of CHWs [28-30]. The remaining 90% of questions were developed/adapted by the authors. The final survey was presented over 27 pages, 13 of which contained core questions addressed to all respondents. Ten pages were conditional on the answers to preceding questions, and the remaining four were exit pages that showed when a participant was not eligible to complete the survey. Below is a brief description of each subsection in the questionnaire (examples of questions for each section are provided in Table 1):

A. *About you*

   As the ECHOES survey is part of the larger EU ESTICOM project and was intended sit alongside EMIS 2017 survey, demographic indicators were harmonised between the two surveys as much as possible. This section contains a total of 11 questions covering age, gender identity (inclusive of trans and gender non-conforming identities), sexual identity (orientation), 'outness', membership of an ethnic or racial minority, location of CHW activities, years in full-time education since the age of 16 years, perception of household income, and languages spoken (native and other). Linking with the final survey section (see J below), some of these items also assessed peer status, namely whether CHWs share characteristics with the populations they serve.

B. *Job employment and status*

   This section asks about the CHW job role (paid or unpaid) in providing sexual health support to gay, bisexual and other MSM. If not currently employed as a CHW, respondents are asked to answer about their most recent CHW role in the last 12 months. Given CHW is an unfamiliar term in Europe, the first question asked participants to describe their job role (open question). Additional questions included: employment status and job security (if part-time additional questions on status when not

working as a CHW); affiliated organisation (if any) including its main purpose, size, and funding sources.

C. *Role as a CHW*

One of the key aims of the ECHOES survey is to find out what CHWs actually do. This section therefore asks respondents about their personal involvement in CHW activities over the last 12 months relating to the sexual health support to gay, bisexual and other MSM around HIV/AIDS, viral hepatitis or other STIs. The cognitive debriefing interviews highlighted that CHWs work in a wide variety of organisations, beyond organisations specialising in gay/bisexual/MSM's sexual health and/or HIV/AIDS. Given the complexity of these CHW roles (practices) within diverse contexts, the wording of questions and data items throughout this section (and the wider survey) are designed to capture responses from: Those who have a CHW role as part of their wider job; those who volunteer unpaid; those who do not currently have a CHW role but did within the past 12 months, and; those whose CHW role involves gay/bi/MSM as well as those who do not fall into this grouping (e.g. heterosexual men, women, etc). This section thus comprises three large sub-sections including prevention, screening and/or testing, and treatment and/or support with each sub-section containing multiple items. Each sub-section covers specific CHW activities and their frequency as well as the settings in which they occur.

D. *Clients*

People CHWs work with and relationship with them. This section asks which populations the CHW works most often with including their approximate age band (<25, >25, even mix) and how many clients they see in a seven-day period as well as their perceptions of client trust in their support and their associate organisation (if relevant).

E. *Barriers to CHW activities*

This section comprises 6 questions asking respondents about the issues which shape (hinder) their role and activities as a CHW at different levels (individual, organisational, societal/cultural) including how things might be improved.

F. *Recruitment as a CHW*

8 items refer to how CHWs were recruited to their post when they first started as a CHW or first got involved with activities supporting gay, bisexual, and other MSM including whether training, qualifications, and/or experience were required.

G. *Training and skills*

A key part of the ECHOES survey is to identify training needs to inform the 3rd objective of the ESTICOM project (development of a specific training programme for CHWs). In this section, 11 questions explore training received, intensity (amount), on-going or not, and topic areas covered, as

well as who identified and paid for the training, whether training is allowed in work time, and requirements (and priority) for future training.

H. Thoughts and feelings about being a CHW

This section included 2 validated scales including: i) an adapted and shortened general self-efficacy scale (6 items) by Romppel et al. [28] based on Schwarzer et al. [29], and; ii) a 10-item shortened version scale similar to Goetz et al [30] to assess job satisfaction including a global job satisfaction rating.

I. Knowledge

For practical purposes and because the ECHOES survey is designed to inform training needs, knowledge of HIV/AIDS, viral hepatitis, and other STIs as a CHW was assessed in terms of confidence judgements regarding core knowledge domains. CHWs were asked to rate how confident they were in their knowledge of HIV/AIDS, viral hepatitis and STIs on a scale from 1 (not confident at all) to 5 (very confident) in three different areas: (1) prevention, (2) screening and/or testing, (3) treatment and/or support, drawing on self-efficacy theory [31]; for a practical example see [32].

J. Final questions

The final 12 questions of the survey are designed to understand how CHWs may be connected to the communities they serve. Five of these comprised the WHO-5 Brief Wellbeing Index [33] to assess general wellbeing and/or good emotional and positive aspects of mental health. A single question assessed overall health, and remaining questions assessed aspects relating to assessing whether CHWs shared some characteristics with the populations they serve (namely living with HIV, drug use etc.).

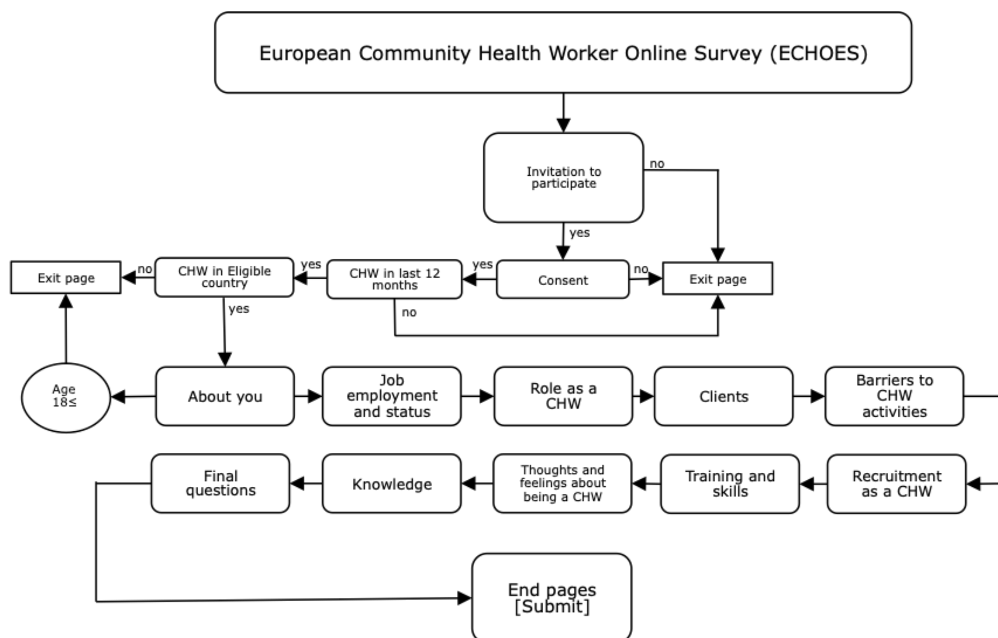

Figure 2. Flow diagram of ECHOES questionnaire structure.

Section	Examples of ECHOES question (s)
A. About you	• Which of the following best describes how you think of yourself [gender identity response-set]; …is this what you were assigned at birth? [trans experience; y/n] • Which of the following best describes how you think about yourself? (sexual orientation response-set); Thinking about all the people who know you (including family, friends and work or study colleagues), what proportion know this? [outness response-set]
B. Job employment and status	• We know that many people do not use the term 'Community Health Worker'. How would you describe your job title? [free-text] • When working as a CHW, which of the following best describes the type of organisation you work for/with? [organisation response-set]
C. Role as a CHW	• Tick all that apply: ▪ For the purposes of prevention, I am involved in providing information about… [information response-set e.g. safer sex, testing, vaccinations, chemsex] ▪ I am involved in providing these intervention activities……[intervention response-set e.g. supporting use of PreP/PEP, sexual health provision, mental health support] ▪ Where do you deliver prevention activities around HIV/AIDS, viral hepatitis and STIs to gay, bisexual and other MSM? [settings response-set e.g. gay venues]
D. Clients	• Which three of these populations of people do you most often work with in your CHW activities? [population response-set] • Thinking only about your work with gay, bisexual and other MSM regarding delivering sexual health support on HIV, viral hepatitis and other STIs, what age group do you most often work with? [age response-set]
E. Barriers to CHW activities	• Think about all the activities you do in your role as a CHW. Please tick the main issues for you as an individual which hinder your activities [individual barriers response-set] • Please tick the main issues from your organisation which hinder your activities [organisational barriers response-set]
F. Recruitment as a CHW	• Why did you start to work/volunteer as a CHW? [motivation response-set] • How did you first become a CHW?
G. Training and skills	• Thinking about your current role as a CHW, have you received training in this role? [if yes - What kind of training have you received? [training type response-set] • In order to be as effective as possible in your current role, which areas would you most benefit from additional training in? [training areas response-set]
H. Thoughts and feelings about being a CHW	• Please think about your day to day life, including your role as a CHW. How true are the following statements? [true/not true response-set] ▪ It is easy for me to stick to my aims and accomplish my goals. ▪ I am confident that I could deal efficiently with unexpected events. ▪ Thanks to my resourcefulness, I know how to handle unforeseen situations. • Taking everything into consideration, how do you feel about your activities as a CHW as a whole? [satisfaction response-set)
I. Knowledge	• Regarding HIV/AIDS/ Hepatitis B and C, how confident are you in your knowledge of... prevention; screening and/or testing; treatment and/or support? [HIV/AIDS/ Hepatitis B and C, confidence response-set]
J. Final questions	• Have you ever been diagnosed with HIV? • How good is your health in general? [general health status response-set] • …Please indicate which is closest to how you've been feeling over the last two weeks: [time response-set] ▪ I have felt cheerful and in good spirits ▪ I have felt calm and relaxed ▪ I have felt active and vigorous ▪ I woke up feeling fresh and rested ▪ My daily life has been filled with things that interest me

Table 1. Examples of ECHOES questions per section

Translation and socio-linguistic equivalence

To facilitate translation, the Demographix platform provided a custom interface for the translation of the signed-off English language version of the ECHOES questionnaire to all required languages. The interface allowed translators to enter the survey via a unique and personalised URL and to see a locked version of the original English version on the left of their screen while translating the survey directly over the top of a second version of the English original, on the right of their screen. Using this service ensured that all

questions maintained the same routing and piping instructions in all languages, and all versions were structurally identical. Demographix also provided existing pre-translated survey completion instructions (for example, next, previous, submit) in all the required languages for ECHOES.

Multilingual proof-readers were asked to use a similar system to compare and contrast survey translations. Demographix also allowed simultaneous access to all ECHOES partners who needed to review a specific version of the survey, prior to being published and launched. Translations were outsourced to translators suggested by the project's collaborating partners, thereby minimising costs. Translations involved native-speaking stakeholders from the field (such as experts in HIV prevention or in lesbian, gay, bisexual, and trans (LGBT) health) as translators for each language. Two multi-language proof-readers were involved where possible to compare the translations not only with the English original but also with each other. The proof-readers ensured a harmonised multi-language questionnaire, while deliberately maintaining certain differences identified as culturally appropriate, such as explicitness of language, or the question of formal or informal address.

In ECHOES, the standardised scales used (see above) came with existing translations. The generalised self-efficacy scale and the WHO-5 Brief Wellbeing Index were available in all languages required for the survey. The job satisfaction scale is available in English and German. Translators were asked to use the already-translated versions where possible, and where translations did not exist, to provide their own translation.

The final questionnaire was available in the following 14 EU languages: Bulgarian, Croatian/Serbian, Czech, Dutch, English, Finnish, French, German, Greek, Italian, Polish, Portuguese, Romanian, Spanish. ECHOES was also translated into Russian, as it is a major ethnic minority language, and into Ukrainian. After consultation with Scandinavian (Norway, Sweden, Denmark) and Baltic country representatives (Estonia, Latvia, Lithuania) it was decided not to translate the ECHOES questionnaire into these languages, because the few expected CHW in these countries were assumed to be able to understand and fill in the English or Russian language questionnaires. Therefore, in total ECHOES was available in 16 languages.

Data analysis and management

In general, data analysis will be exploratory although we will be exploring some issues in line with existing research findings; this includes a gradient across Europe (West to East) of stigma and discrimination intensifying. Scale scores will be created for the standardised instruments, following published procedures. To ensure internal consistency of scales for the sample in this survey, internal consistency reliability will be checked with Cronbach's alpha. Descriptive findings will be reported as means and standard deviations for continuous variables, and as numbers and percentages for categorical variables. Descriptive analyses will be

run in SPSS using the overall ECHOES dataset including all language versions of the ECHOES questionnaire. Bivariate analysis including Chi-square tests (or Fisher exact test when appropriate) and Mann-Whitney U tests will be used to determine significant differences between groups, for categorical variables including demographics. Kruskal-Wallis tests will be used for continuous variables. The main results are expected to be publicly available in late 2019.

Only the ECHOES development team at the University of Brighton (UoB) and the data analysis team at the Centre d'Estudis Epidemiològics sobre les Infeccions de Transmissió Sexual i Sida de Catalunya (CEEISCAT) in Badalona, Spain will have access to the data during the study. After the study is completed, UoB and CEEISCAT will make available the relevant data to Consortium partners for analysis as appropriate.

Ethics

Ethical approval for the initial questionnaire design and development activities (cognitive debrief interviews, pre-testing, piloting etc) was obtained from the University of Brighton's School of Health Sciences, School Research Ethics and Governance Panel (SREGP). Additional approval to host the survey online and recruit participants was received from the Hospital Universitari Germans Trias i Pujol in Badalona, Catalonia (Spain) (PI-16-143), as the hosting institution of CEEISCAT.

Informed 'Opt-In' consent

Respondents who accepted the invitation to take part in the ECHOES study and use the link provided to access the survey web page, were taken to the survey introductory page. Participants were then provided with information about the project, confidentiality of the survey findings, and an outline of what participants were required to do and how long it would take to complete the questions. A statement is then provided regarding data protection including confidentiality and anonymity as well as a brief statement about the ESTICOM project consortium. Potential participants were asked to click on a box to confirm that they had read and understood the participant information before proceeding, a box to confirm that they understood their participation would be voluntary and that they would be able to withdraw at any time, and finally a box explicitly requesting them to 'opt-in' thus confirming their agreement to take part in the survey.

Confidentiality

No personal data (such as names, addresses, date of birth) were collected from participants. The survey is completely anonymous, and no IP addresses were stored or downloaded, and no information regarding the origin of the 'click' was collected. No cookies were installed on the potential participant's computer or device.

Planned dissemination

The results of the ECHOES survey will be published in consortium reports submitted to the CHAFEA, in peer-reviewed scientific journals as well as via conference presentations. Results of the study will also be disseminated through the ESTICOM network via MailChimp and supported by AIDS Action Europe, as well as on the ESTICOM project website (www.esticom.eu).

Results

Recruitment closed on 31 January 2018. A total of 1,181 responded to the survey. Responses were screened for key inclusion criteria. Those who did not deliver services to MSM in a community setting (n=107), not working or being active in the countries included in the study (n=24), and not meeting the minimum age of 18 years (n=15) were excluded, resulting in a final sample available for analysis of 1,035 community health workers.

Discussion

To our knowledge, this study is the first internet-based self-completion questionnaire survey exploring the knowledge, attitudes, and practices of Community Health Workers (CHWs) providing sexual health support to gay men, bisexual men and other MSM in European settings. It is expected that the results will transform our understanding of who CHWs in Europe are, what they do, where, how, and why they do what they do, as well as identify the individual, organisational and structural barriers and challenges to CHWs' activities. Moreover, by gaining a deeper understanding of CHWs' knowledge, attitudes, and practices with regards their clients, and given that ECHOES is part of the much larger ESTICOM project which includes the EMIS-2017 survey, findings are also expected to generate insights for the development of the first European common training programme for CHWs (aim 3 of ESTICOM). We expect this impact to be considerable with findings highlighting important areas to strengthen and build the capacity of CHWs in all the 36 ECHOES eligible countries (all 28 EU countries and neighbour countries including Bosnia Herzegovina, Iceland, Moldova, Norway, Russia, Serbia, Switzerland, and Ukraine).

The questionnaire will also garner information about profile characteristics of CHWs which may be important in supporting CHWs, allowing them to develop their professional profile and informing of psycho-social training needs. This will be supported by information on both general and emotional health, job satisfaction and acceptance of gay/bisexual and MSM people.

The pan-European nature of this study will provide a comprehensive data set across participating countries which will enable analysis of variability observed in CHWs knowledge, attitudes, and practices. As the output of a European Commission tender, it is anticipated that this knowledge of the variability between CHWs

along with insights for the development of common training will be important in the development of future policy initiatives around promoting health, reducing new infections, and ultimately working towards global Sustainable Development Goals (SDGs; Goals 3, 10, 11) and achieving the UNAIDS 90/90/90 targets.

Acknowledgements

All authors were involved in the conceptualisation, drafting, and critical review of this manuscript. Funded by the Consumers, Health, Agriculture and Food Executive Agency (CHAFEA) of the European Commission. Thanks are due to survey participants, and all those who provided invaluable feedback during pre-testing, the cognitive debrief phase, and piloting. Thanks also, to all the country collaborators across Europe who supported the translation of the survey, as well as to the local multipliers for their efforts in promoting the survey to potential participants. Finally, our thanks to the ESTICOM project advisory board.

Conflicts of Interest

None declared.

References

1. Elford J, Hart G, Sherr L. Peer led HIV prevention among homosexual men in Britain. Sexually Transmitted Infections. 2002; 78:158-159.
2. Kelly JA. Popular opinion leaders and HIV prevention peer education: Resolving discrepant findings, and implications for the development of effective community programmes. AIDS Care. 2004;16(2):139-5.
3. American Public Health Association. Recognition and Support for Community Health Workers' Contributions to Meeting our Nation's Health Care Needs. Policy Number 200115. APHA, 2001. URL https://www.apha.org/policies-and-advocacy/public-health-policy-statements/policy-database/2014/07/15/13/24/recognition-and-support-community-health-workers-contrib-to-meeting-our-nations-health-care-needs [Accessed 11th June 2019]
4. Lefeuvre D, Dieng M, Lamara F, Raguin G, Michon C. Community health workers in HIV/AIDS care. Sante publique. 2014; 26:879.
5. Goodwin K, Tobler L. Community health workers expanding the scope of the health care delivery system. National Conference of State Legislatures. 2008. URL http://www.ncsl.org/print/health/CHWBrief.pdf [Accessed 19th September 2019]
6. Ingram M, Reinschmidt KM, Schachter KA, Davidson CL, Sabo SJ, De Zapien JG, Carvajal SC. Establishing a professional profile of community health workers: results from a national study of roles, activities and training. *J Community Health.* 2012;37(2):529-37.

7. National Community Health Worker Advocacy Survey. Preliminary Data Report for the United States and Territories. Arizona Prevention Research Center, Zuckerman College of Public Health, University of Arizona.2014. URL http://www.michwa.org/wp-content/uploads/2014-NCHWAS.pdf [Accessed 19th September 2019]
8. Mwai GW, Mburu G, Torpey K, Frost P, Ford N, Seeley J. Role and outcomes of community health workers in HIV care in sub-Saharan Africa: a systematic review. J Int AIDS Soc. 2013;16(1):18586.
9. Nyamathi A. Engaging Community Health Workers in HIV/AIDS Care: A Case Exemplar Among Rural Indian Women Living With AIDS. Journal of HIV/AIDS & Social Services. 2014;13(4):330-336
10. Schneider H, Hlophe H, van Rensburg D. Community health workers and the response to HIV/AIDS in South Africa: tensions and prospects. Health Policy and Planning. 2008; 23(3):179-187,
11. Sabo S, Allen CG, Sutkowi K., Wennerstrom A. Community health workers in the United States: Challenges in identifying, surveying, and supporting the workforce, AJPH, 2017;107(12): 1964-1969
12. NICE. Community engagement: improving health and wellbeing and reducing health inequalities (NG44). 2018. URL https://www.nice.org.uk/guidance/ng44/resources/community-engagement-improving-health-and-wellbeing-and-reducing-health-inequalities-pdf-1837452829381. [Accessed 19th September 2019]
13. Olaniran A, Smith H, Unkels R, Bar-Zeev S, van den Broek N. Who is a community health worker? A systematic review of definitions. Global Health Action. 2017;10(1), DOI: 10.1080/16549716.2017.1272223.
14. World Health Organization. Global strategy on human resources for health: Workforce 2030. Geneva: WHO. 2016. URL https://apps.who.int/iris/bitstream/handle/10665/250368/9789241511131-eng.pdf?sequence=1&ua=1. [Accessed 19th September 2019]
15. European Centre for Disease Prevention and Control/WHO Regional Office for Europe. HIV/AIDS surveillance in Europe 2018 – 2017 data. Copenhagen: WHO Regional Office for Europe; 2018.
16. Batchelder AW, Safren S, Mitchell AD, Ivardic I, O'Cleirigh C. Mental health in 2020 for men who have sex with men in the United States. Sexual Health. 2017; 14(1), 59.
17. HIV and AIDS in Eastern Europe & Central Asia Overview. AVERT. URL https://www.avert.org/printpdf/node/2216 [Accessed 19th September 2019]
18. Mikkonen M, Kauppinen J, Huovinen M, Aalto E (Eds). Outreach work among marginalised populations in Europe: Guidelines on providing integrated outreach services. Amsterdam: Foundation Regenboog AMOC. 2007.
19. South J, Meah A, Bagnall AM, Kinsella K, Branney P, White J, Gamsu M. People in public health - A study of approaches to develop and support people in public health roles. Report for the National Institute for Health Research. London: HMSO; 2010. URL

http://www.netscc.ac.uk/hsdr/files/project/SDO_FR_08-1716-206_V01.pdf [Accessed 19th September 2019]

20. South J. The community health apprentices project – the outcomes of an intermediate labour market project in the community health sector. Centre for Health Promotion Research, Leeds Metropolitan University, Leeds, UK. 2011. URL https://core.ac.uk/display/29018641/tab/similar-list. [Accessed 19th September 2019]
21. World Health Organization. Community health workers: What do we know about them? The state of the evidence on programmes, activities, costs and impact on health outcomes of using community health workers. Geneva: WHO. 2007.
22. Sherriff NS, Huber J, McGlynn N, Llewellyn C. A final proposal for a European community health worker survey (ECHOES). Luxembourg, European Union (EU). 2017. URL https://research.brighton.ac.uk/en/publications/d62-a-final-proposal-for-a-european-community-health-worker-surve [Accessed 19th September 2019]
23. Lorente N, Folch C, Aussò S, Sherriff N, Huber J, Panochenko O, Krone M, Marcus U, Schink S, Dutarte M, Kuske M, Casabona J. European Community Health Worker Online Survey (ECHOES): Final report. Barcelona: CEEISCAT; 2019. URL https://research.brighton.ac.uk/en/publications/european-community-health-worker-online-survey-echoes-final-repor [Accessed 19th September 2019]
24. Folch C, Fernández-Dávila P, Palacio-Vieira J, Dutarte M, Maria-Corbelli G, Block K. A Review of Community Health Worker (CHW) knowledge, attitudes and practices relating to the sexual health of MSM, including existing training materials and manuals in Europe and neighbouring countries. Luxembourg: European Union (EU). 2017. URL https://www.hareact.eu/ru/node/5300 [Accessed 19th September 2019]
25. Ajzen I. The theory of planned behavior. Organizational Behavior and Human Decision Processes. 1991;50(2):179-211.
26. Ajzen I, Fishbein, M. Understanding attitudes and predicting social behavior. Englewood Cliffs: Prentice Hall. 1980.
27. Becker MH, Maimon LA. Sociobehavioral determinants of compliance with health and medical care recommendations. Medical Care. 1975;13(1):10-24.
28. Romppel M, Herrmann-Lingen C, Wachter R, Edelmann F, Düngen HD, Pieske B, Grande G. A short form of the General Self-Efficacy Scale (GSE-6): Development, psychometric properties and validity in an intercultural non-clinical sample and a sample of patients at risk for heart failure. Psychosocial Medicine. 2013;10:1-7.
29. Schwarzer R, Jerusalem M. Generalized Self-Efficacy scale. In: Weinman J, Wright S, Johnston M, eds. Measures in health psychology: A user's portfolio. Causal and control beliefs. Windsor, UK: NFER-NELSON; 1995;35-7.

30. Goetz K, Campbell SM, Steinhaeuser J, Broge B, Willms S, Szecsenyi J. Evaluation of job satisfaction of practice staff and general practitioners: an exploratory study. BMC Family Practice 2011;12:137.
31. Bandura A. Self-efficacy: toward a unifying theory of behavioral change. Psychological Review. 1977;84(2):191-215.
32. Styles I, Volet S. Development and psychometric evaluation of scales to measure professional confidence in manual medicine: a Rasch measurement approach. BMC Research Notes; 2014;7: 338.
33. Bech P. Quality of life in the psychiatric patient. London: Mosby-Wolfe; 1998.

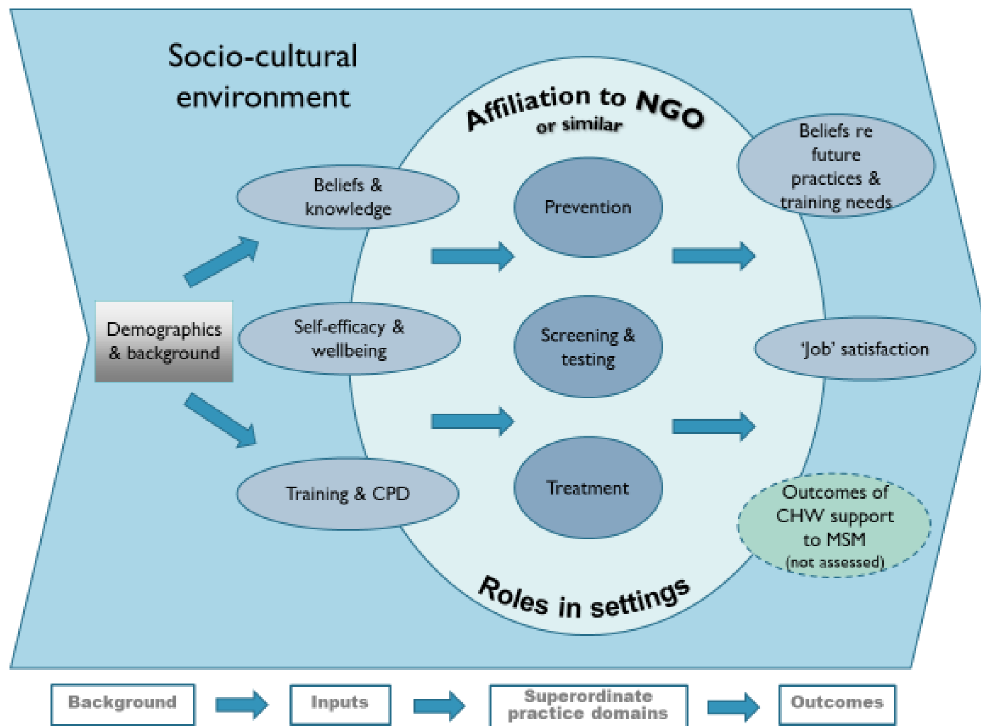

Figure 1. Diagram of ECHOES conceptual model

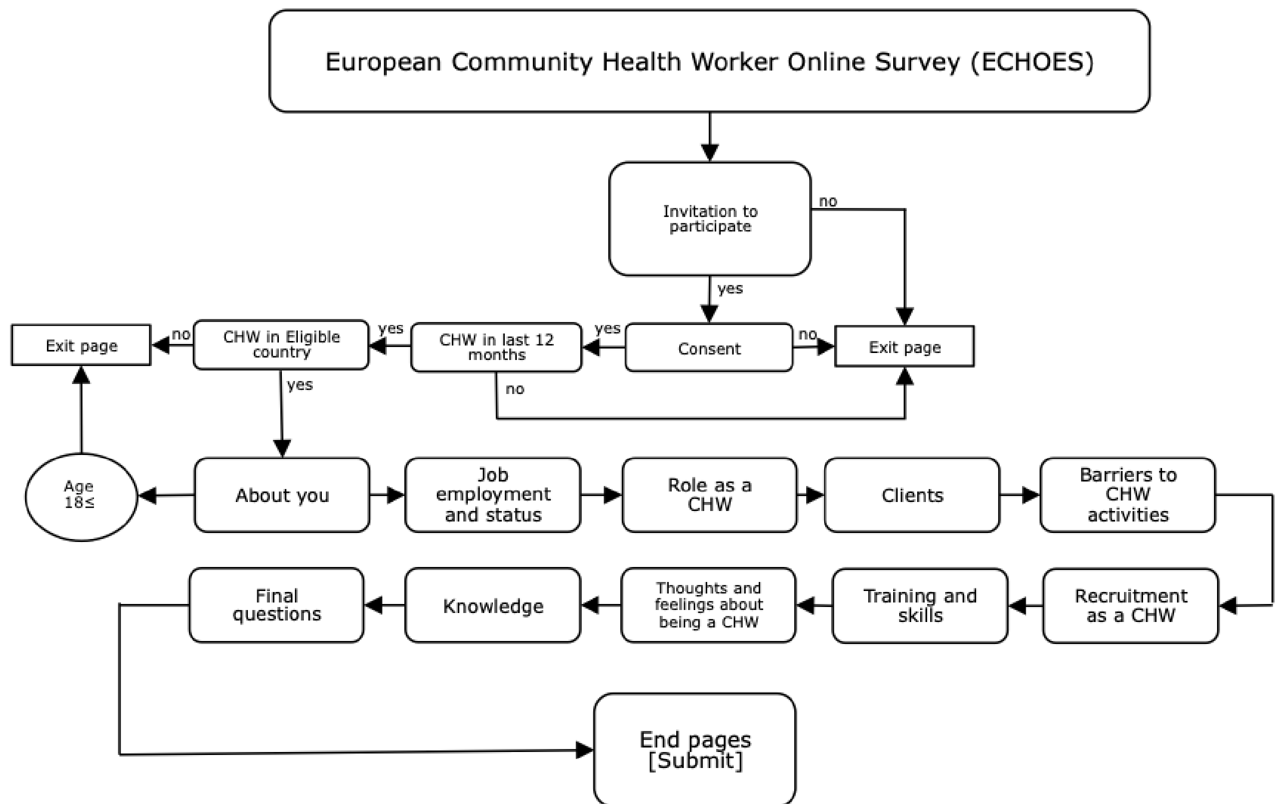

Figure 2. Flow diagram of ECHOES questionnaire structure.

Section	Examples of ECHOES question (s)
A. About you	• Which of the following best describes how you think of yourself [gender identity response-set]; …is this what you were assigned at birth? [trans experience; y/n] • Which of the following best describes how you think about yourself? (sexual orientation response-set); Thinking about all the people who know you (including family, friends and work or study colleagues), what proportion know this? [outness response-set]
B. Job employment and status	• We know that many people do not use the term 'Community Health Worker'. How would you describe your job title? [free-text] • When working as a CHW, which of the following best describes the type of organisation you work for/with? [organisation response-set]
C. Role as a CHW	• Tick all that apply: ▪ For the purposes of prevention, I am involved in providing information about… [information response-set e.g. safer sex, testing, vaccinations, chemsex] ▪ I am involved in providing these intervention activities……[intervention response-set e.g. supporting use of PreP/PEP, sexual health provision, mental health support] ▪ Where do you deliver prevention activities around HIV/AIDS, viral hepatitis and STIs to gay, bisexual and other MSM? [settings response-set e.g. gay venues]
D. Clients	• Which three of these populations of people do you most often work with in your CHW activities? [population response-set] • Thinking only about your work with gay, bisexual and other MSM regarding delivering sexual health support on HIV, viral hepatitis and other STIs, what age group do you most often work with? [age response-set]
E. Barriers to CHW activities	• Think about all the activities you do in your role as a CHW. Please tick the main issues for you as an individual which hinder your activities [individual barriers response-set] • Please tick the main issues from your organisation which hinder your activities [organisational barriers response-set]
F. Recruitment as a CHW	• Why did you start to work/volunteer as a CHW? [motivation response-set] • How did you first become a CHW?
G. Training and skills	• Thinking about your current role as a CHW, have you received training in this role? [if yes - What kind of training have you received? [training type response-set] • In order to be as effective as possible in your current role, which areas would you most benefit from additional training in? [training areas response-set]
H. Thoughts and feelings about being a CHW	• Please think about your day to day life, including your role as a CHW. How true are the following statements? [true/not true response-set] ▪ It is easy for me to stick to my aims and accomplish my goals. ▪ I am confident that I could deal efficiently with unexpected events. ▪ Thanks to my resourcefulness, I know how to handle unforeseen situations. • Taking everything into consideration, how do you feel about your activities as a CHW as a whole? [satisfaction response-set)
I. Knowledge	• Regarding HIV/AIDS/ Hepatitis B and C, how confident are you in your knowledge of... prevention; screening and/or testing; treatment and/or support? [HIV/AIDS/ Hepatitis B and C, confidence response-set]
J. Final questions	• Have you ever been diagnosed with HIV? • How good is your health in general? [general health status response-set] • …Please indicate which is closest to how you've been feeling over the last two weeks: [time response-set] ▪ I have felt cheerful and in good spirits ▪ I have felt calm and relaxed ▪ I have felt active and vigorous ▪ I woke up feeling fresh and rested ▪ My daily life has been filled with things that interest me

Table 1. Examples of ECHOES questions