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A rapid evidence review of health advocacy for communicable diseases

Insights into health communication

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ECDC TECHNICAL REPORT

A rapid evidence review of health advocacy for communicable diseases

Insights into health communication
This evidence review was commissioned by the European Centre for Disease Prevention and Control (ECDC) as one of the outputs of the Framework Partnership Agreement Grant/2009/007 "Establishing a programme for dissemination of evidence-based health communication activities and innovations on communicable diseases for country Support in the EU and EEA/EFTA, 2009–12", with a consortium of universities comprised of the Health Promotion Research Centre at the National University of Ireland Galway, as the lead coordinating centre, and the Institute for Social Marketing, University of Stirling, Scotland, and the University of Navarra Clinic, Pamplona, Spain.

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# Abbreviations

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<tr>
<td>ACSM</td>
<td>Advocacy, communication and social mobilisation</td>
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<td>DOTS</td>
<td>Directly Observed Treatment Short course</td>
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<td>ECDC</td>
<td>European Centre for Disease Prevention and Control</td>
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<td>EEA</td>
<td>European Economic Area</td>
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<td>IDF</td>
<td>International Diabetes Foundation</td>
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<td>IDU</td>
<td>Injecting drug user</td>
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<td>PLWHA</td>
<td>People living with HIV/AIDS</td>
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<td>TB</td>
<td>Tuberculosis</td>
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<td>WHO</td>
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Executive summary

Background
Advocacy has been identified as a key strategy for health promotion and public health and a powerful tool to promote equity. In the context of public health, advocacy strives to optimise health by addressing the environmental, social, political and economic factors that impact on health and seeks to influence the policies and practices that create the conditions for change [1]. This report is a rapid review of the evidence on public health advocacy for communicable diseases.

Objectives
This evidence review seeks to examine and encapsulate international evidence on public health advocacy initiatives, to identify gaps in the evidence, and to provide recommendations.

Findings
No evidence reviews of public health advocacy initiatives for communicable diseases were found in the literature. However, this review did identify a range of sources of evaluated health advocacy interventions, models and toolkits, and examples of best practice in the wider health advocacy arena that could be used to inform the development of effective strategies and resources for communicable disease.

A North American review identified the characteristics of public health advocacy campaigns that were effective in changing industry practices that damage health [2]. The reviewers identified that most campaigns employed multiple strategies and that at least half the campaigns used the three strategies of coalition building, media advocacy and public mobilisation. The importance of the social context to the success of a campaign was underscored in this review.

Toolkits have been developed by advocacy organisations to provide high quality resources for use by experienced and novice health advocates. These resources include templates for letters and publicity, advice on engaging the media and relevant stakeholders, and key messages about the issue of concern. An examination of a number of these toolkits identified a level of overlap that suggests a common base of core components and principles for effective advocacy across different topics.

The methodological challenges of evaluating advocacy initiatives provide a forceful argument for adopting a more considered and systematic approach to evaluation. Recent developments have strengthened the knowledge base for such evaluations, and the recommended utilisation of a theory of change benefits the development of an advocacy initiative by making explicit the intended relationship between actions and outcomes.

Conclusions
Health advocacy for communicable diseases is clearly still at a nascent stage and the current evidence base is very underdeveloped. The duration and complexity of public health advocacy campaigns and initiatives makes the need for theory-based evidence imperative. The shared consensus in the literature about core components of health advocacy initiatives and the existence of templates and toolkits in the area means that foundations do exist upon which to advance advocacy for the prevention of communicable diseases.
Introduction

This paper reports on a rapid review of the evidence on public health advocacy for communicable diseases. The review aimed to identify evidence of:

- effective approaches and activities relating to health advocacy and communicable disease
- evaluations of such activities and approaches
- the extent to which these activities and approaches have been targeted to minority/disadvantaged and hard-to-reach populations.

This rapid review on health advocacy forms part of a series of evidence reviews commissioned by the European Centre for Disease Prevention and Control (ECDC) through the Translating Health Communications Project, which is concerned with the dissemination of evidence-based health communication activities in the EU and EEA countries (2009–2012).

Advocacy

The term advocacy entered the English language common lexicon in the 1960s [3] although, as a concept, it is based on traditional notions, ‘of civil society and of the citizen as one who takes responsibility not just for him or herself but for his/her neighbour and for the process of change’ [4].

An underlying principle of advocacy is the representation or empowerment of vulnerable people [4] and advocacy can be viewed as a tool towards equity. The word advocacy, with its underlying concept, does not translate directly into many other languages and many words may be needed to approximate the meaning [5, 6]. Even in the English language, advocacy is subject to a variety of definitions and understandings many of which are dependent on the context in which the term is being used. Typographies do not signify a clarity or consensus as to a precise definition.

Carlisle cites Rees’ simple classification of advocacy into ‘cases’ and ‘causes’; case advocacy includes the representation of underprivileged people, including the sick, to promote their rights and/or redress power imbalances [7]. Such advocacy is now a component part of many health services with access to advocacy services provided for in government policies and in legislation – particularly those concerning mental health, mental capacity, disability rights and the safeguarding of children and vulnerable adults [8]. ‘Causes’ advocacy includes lobbying activity within public health in recognition of the importance of addressing factors outside the control of individuals in order to reduce health inequalities. Clearly, both ‘cases’ and ‘causes’ advocacy have a fundamental focus on reducing health inequalities.

The Ottawa Charter for Health Promotion [9] identified advocacy as one of the three major strategies for health promotion, and the World Health Organization later defined advocacy for health as, ‘a combination of individual and social actions designed to gain the political commitment, policy support, social acceptance and systems support for a particular health goal or programme [10].’

However, Shilton in 2006 pointed out the inconsistency which he noted between the widespread acceptance of advocacy as a priority strategy and its underdeveloped nature in the arenas of health promotion and public health [11].

Advocacy and health professionals

In 2004 the paucity of attention devoted to advocacy in Masters of Public Health programmes was decried [12]. However, in the intervening years professional education and training for health advocacy has increased. A policy statement from the UK’s Royal College of Physicians in 2010 called on all members of the medical profession to advocate health equality in order to effectively tackle the social determinants of health. The entire profession, the document states, ‘can use their powerful voices, whether on a personal, community or national level, to promote actions on the social determinants of health [13].’

Likewise, a recent statement from the International Council of Nurses cites advocacy as a core competence of health professionals, [5] and the Association of Schools of Public Health in the European Region have a working group – Public Health Advocacy and Communication – dedicated to motivating, ‘schools of public health to promote academic and advanced training programmes based on evidence and research related to advocacy’ [14].

However, such developments are not without some controversy and Johnston suggests that the inclusion of public health advocacy strategies into public health education may challenge the traditional epistemological foundations of public health education, ‘much of which is grounded in the concept of scientific neutrality, and the belief in the possibility of ‘value-free’ research [15].’
Public health advocacy

The remit of public health encompasses not just the individual, but seeks to optimise health by addressing the environmental, social, political and economic factors that impact on health and influencing the policies and practices that create the conditions for change [1].

Public health advocacy has been characterised as ‘policy advocacy’ which targets those whose actions can impact the lives of ‘many people simultaneously’ and it, ‘takes personal problems and translates them into social issues, addressing determinants of health which are external to the individual such as basic housing, employment, education, health care, and personal security’ [16].

The World Health Organization stresses the critical essence of the term ‘policy’ defining it as, ‘how societies and their institutions deal with any issue. Policies may be written (such as laws) or unwritten (for example, etiquette or social mores). Policy can be formal (a national AIDS strategy) or informal (the fact that some workplaces do not want to employ people living with HIV/AIDS)’ [6].

Public health advocacy strives to reduce morbidity and mortality but it also brings about a number of intermediate outcomes including the enhancing of community or group dynamics and changes in behaviour which support or promote good health [17]. Likewise, health advocacy can take place at a supranational or global level and is a component part of many programmes funded in the developing world. Advocacy on a particular issue may take place simultaneously and may interact with each other, ‘work at the national level affects the community level and vice versa, and policy changes at the global or regional level are often followed by national revisions in policies and practices’ [6].

Strategies that are used in pursuance of advocacy goals are as multifaceted as the diversity of advocacy programmes, and advocacy may constitute a stand-alone service or be a component of a complex, agency intervention [18]. The World Health Organization (WHO) identifies that the lifeblood of all effective advocacy is ‘strategic communication’ [19] and the function of all advocacy is educating and mobilising people to meet needs.
Methodology

This rapid evidence review seeks to examine and encapsulate recent international evidence on advocacy initiatives for communicable diseases, including assessments and evaluations of such programmes and interventions. The literature was examined for such evidence in relation to communicable disease with particular regard to that which concerned minority, disadvantaged or ‘hard-to-reach’ populations.

The review is focused on public health advocacy strategies, toolkits and their evaluation with particular regard to initiatives and/or evidence relating to three communicable diseases; Tuberculosis (TB), HIV/AIDS and measles. These communicable diseases were selected due to their relevance in the European context. An initial database search was carried that included the following:

Databases

- SCOPUS - the world’s largest abstract and citation database of peer-reviewed literature and quality web sources
- Web of Knowledge – a citation indexing and search service covering the sciences, social sciences, arts and humanities
- EBSCO – the following databases were selected from the EBSCO database: Academic Search Complete, CINAHL; Health Source; Medline; Psychology and Behavioural Sciences Collection; SocIndex and ERIC
- DARE – Database of Abstracts of Reviews of Effects
- HealthComm Key - database containing comprehensive summaries from published peer-reviewed studies related to health communication
- The Cochrane Library.

Search Strategy

- **Search terms included:** ("health advocacy" OR "health advocacy activities" OR "health advocacy interventions") AND ("communicable disease OR "public health" OR "measles" OR "HIV" OR "AIDS" OR "TB") AND ("evidence" OR "evaluation")
- **Languages consulted:** English
- **Geographical spread:** initially Europe, subsequently worldwide
- **Time frame:** 2000 to 2011
- **Types of literature:** peer reviewed literature from the databases listed above plus the archives of the Journal of Health Communication were searched as were the websites of ECDC and WHO. In addition, the reference lists and the citations of the retrieved documents were searched.

The literature search revealed a lack of evidence relating to health advocacy in general and an almost complete absence of evidence relating to health advocacy for communicable diseases; only one published review of health advocacy interventions was located. The search was then expanded to a range of sources to identify evaluated health advocacy initiatives, advocacy models, toolkits and other resources for health advocacy and methodologies for evaluating health advocacy initiatives.

These sources were reviewed to identify common ground and best practice to inform the development of effective strategies in the realm of communicable diseases. These sources include evidence reviews in the literature, advocacy models and methodologies for evaluation, existing toolkits, and examples of evaluated initiatives.
Findings

Review of health advocacy campaigns

There is a virtual absence in the literature of reviews of public health advocacy campaigns. However, a 2009 review by Freudenberg et al., sought to identify the characteristics of public health campaigns deemed to have been effective in changing industry practices that damage health [2]. For the purpose of their review, the authors defined a campaign as, ‘an advocacy initiative in which one or more organisations mounted targeted activities of variable duration designed to achieve explicit changes in corporate or industry practices perceived to harm health’ [2].

The inclusion criteria for the campaigns were that they:

- targeted a specific practice in one of the following industries: alcohol, automobile, firearms, food and beverages, pharmaceuticals or tobacco
- were designed to influence corporate practice
- clearly identified and defined the health objectives of the initiative.

The authors used a multiple case history design because, they state, such a design can result in findings that are generalisable to other settings. Twenty-five campaigns met the review criteria from which a convenience sample of 12 campaigns was taken, representing two from each of the six target industries. To qualify for inclusion it was required that evidence was available from at least three separate sources and that two of these sources were independent of the campaign; such sources could include media or advocacy reports, government, or industry documents. The authors included: 12 North American campaigns; identified the use of 11 strategies; listed the stakeholders most commonly involved with the advocacy campaign; and, ranked the advocacy campaigns according to their success. The results demonstrate the range of both strategies employed and stakeholders involved in such campaigns, and it is notable that the advocates targeted not only their ‘opponents’ but also a wide range of other stakeholders [2].
The reviewers rated the success of each campaign across two criteria: the extent to which the campaign reached its stated objectives and its success in mobilising constituencies. The reviewers acknowledge that evidence of the change in corporate practice is not evidence of health impact but contend that, ‘there is substantial plausible epidemiological evidence that these changes in practice can contribute to improvements in health’ [2]. They also suggest that useful indicators of success were identifiable and these indicators could be used in future campaigns:

- short term markers including an articulation of the targeted changes which the campaigners want to achieve and the establishment of a coalition
- intermediate markers including generating favourable media coverage, a favourable reframing of the issue and policy change
- long-term markers including sustained changes in corporate practice.
The reviewers identified that most campaigns employed multiple strategies and that at least half the campaigns used the three strategies of coalition building, media advocacy and public mobilisation. The other most frequently used strategies were listed as: public advocacy, community organisation, litigation, letter writing and public protest. Freudenberg et al., considered the response of the target industry to the campaign and identified two frequent responses:

- two common responses were to ignore opponents, often possible in the circumstances in which health advocates had far fewer resources than their industry opponents, or to adopt a more aggressive stance, publically denying advocates’ claims, defending their own practices and delaying action through use of political processes [2].

The strategies employed by ‘the opponents’ to respond to the campaign were often similar to those used against them and included media advocacy, lobbying, litigation and the promotion of scientific evidence.

The reviewers noted that many of the campaigns were framed around freedom, rights, truth and honesty, and several groups introduced a social justice frame. The protection of children and young people was the focus of a number of the campaigns - a finding compatible with previous literature [20] – and a cause of concern for the reviewers because of the exclusion of the more stigmatised populations who, like children, are ‘often targeted by industries promoting dangerous products’ [2].

Interestingly, the component that the reviewers concluded was ‘critical’ to a campaign’s success was the social context within which they took place. The anti-tobacco campaign took place in a more favourable national and local context than did the gun control campaign and this was reflected in the relative success of the campaign. However, context is not fixed but is subject to change as the ‘Coca-Cola’ campaign illustrated; this campaign started at a time when the dominant concern of the district school board was financial and was won finally at a time of mounting public concern about childhood obesity. The local nature of the Coca-Cola campaign may also have contributed to its success as the local campaigns included in the review were more effective than the national ones.

The authors acknowledged a number of limitations to their research including sampling limitations, the lack of investigation into the financial resources of the campaigns and the lack of a standardised measure to assess effectiveness. Nevertheless, they conclude that the evidence demonstrates that public health advocates can successfully change health-damaging practices and argue that health advocates may be able to optimise their own campaigns by employing strategies proving to be effective. In furtherance of that, ‘health educators, advocates and researchers need to continue to collaborate to identify characteristics of effective campaigns’ [2].

**Advocacy models**

A number of models or strategies have been developed to enhance effective advocacy. Shilton was an early proponent of the role of advocacy to promote the importance of physical activity and in 2006 proposed a three-step model of advocacy [11]. The three steps were labelled the ‘why’, ‘what’ and ‘how/who’, and are reproduced by the Advocacy Council of the International Society for Physical Activity and Health (ISPAH) in their advocacy policy [21]. This advocacy policy is actively supported by the International Union for Health Promotion and Education.

The stated core functions of the Advocacy Council of the International Society for Physical Activity include reference to Shilton’s development of the model [11] with the addition of ‘five imperatives’ for physical activity advocacy [22]. In the outline of the imperatives presented below, the words ‘physical activity’ have been placed within brackets to indicate the transferability of the model. Those words can be logically replaced by words describing a multiplicity of health issues.

The five imperatives are:

- **evidence:** translate and present the (physical activity) evidence as urgent
- **policy relevance:** present (physical activity) as relevant to policy in health and across sectors as urgent
- **solutions:** outline an agenda for action (on physical activity) – ‘a ten point plan’
- **advocacy strategy:** mobilise advocacy strategies across five domains
  - political advocacy
  - media advocacy
  - professional mobilisation
  - community mobilisation
  - advocacy from within organisations
- **persuasive communication:** translate the evidence through persuasive message-framing presenting the argument as urgent, personally relevant and open to solution.

These models usefully demonstrate the transferability of the essentials of advocacy campaigns and indicate that there is an existing body of knowledge which can help to inform the developers of new advocacy campaigns.
The issue of advocacy and an identifiable ‘enemy’ re-occurs in the literature on advocacy. Public health advocacy often depicts advocacy campaigns as a battle between the health advocates and a powerful – often corporate – opponent with public health objectives at odds with governments, industry or other stakeholders [11, 12]. Some campaigns, however, lack a focal opponent. The lack of a tangible opponent is characterised as an added challenge to advocates for physical activity by Shilton, as advocates have to pit themselves against the less tangible but, ‘more pervasive enemies such as apathy, ignorance, political indifference, addiction to labour-saving devices and a ‘couch potato’ attitude’ [11].

However, the lack of an opponent can be counterbalanced by the persuasive framing of a campaign. Freeman et al. [23], described how the framing of the smoking in cars campaign made opposition inconceivable:

> Invoking the protection of vulnerable children in the debate about smoking in cars called up an almost invincibly powerful sub-text for advocates. Unlike all other advocacy for smoke-free areas, this debate was not contested by the tobacco industry or other commercial interest ... With there being no lobby group dedicated to protecting the rights of parents to harm the health of their children, opposition to the proposal was left to those with wider political agendas concerned about usurping parental decision-making and setting a precedent for ‘slippery slope’ state legislative incursions into private space [23].

The campaign to ban smoking in cars in which children are travelling took twelve years from the first evidence of the harm to the passing of legislation by two Australian states [23]. Public health advocacy campaigns may, indeed, be characterised by their length, and arguably the longest lasting public health advocacy campaign has been that waged against tobacco and smoking. The time scale of public health advocacy campaigns has significant implications for the evaluation of such advocacy and is an important consideration for the development of strategic goals for campaigns.

Long-term goals may need to be balanced with short-term pragmatic ones especially in instances where the long-term goals may not be achievable. The World Health Organization offers a relevant example:

> protecting IDUs (Injecting Drug Users) from HIV transmission requires putting programmes and policies in place in the short term. It is therefore necessary to accept that there are IDUs in a society who will not immediately stop injecting and that some young people will probably start injecting each year. The emphasis of advocacy efforts must therefore be on short-term pragmatic goals, such as keeping current IDUs un-infected and alive, without losing sight of the longer term goals such as demand reduction or a drugs free society. [6]

**Toolkits/guides**

Many toolkits have been published as guides to conducting advocacy activities. Four toolkits, that are widely used internationally, will be detailed below to explain common features and to seek evidence as to best practice. Two of the toolkits concern communicable diseases; the third is the World Health Organization’s advocacy toolkit for non-communicable disease and the fourth – concerning diabetes - is included to illustrate some of the materials. The toolkits concerning communicable disease are clearly of particular relevance to this review and the two other toolkits are included to ensure that a breadth of resources is considered. The organisations included in this review are: ACTION Advocacy to Control Tuberculosis Internationally; the International HIV/AIDS Alliance and the International Council of AIDS Service Organisations; the World Health Organization; and the International Diabetes Federation.

**Organisation: Advocacy to Control Tuberculosis Internationally (ACTION)**

ACTION is an international partnership of advocates who work to the premise that, ‘more rapid progress can be made against the global TB epidemic by building increased support for resources for effective TB control among key policymakers and other opinion leaders in both high TB burden countries and donor countries’ [24].

ACTION and one of their partner organisations, RESULTS, provide many toolkits for multiple aspects of advocacy, categorised in a number of ways and representing best tools and tactics [24]. For the beginner it offers a number of guides including:

- how to speak powerfully
- how to write a letter to the editor
- how to ask a question at a community meeting or candidate forum
- how to generate an editorial in your local paper.

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1 Advocacy to Control Tuberculosis Internationally (ACTION) [http://www.action.org/site/about_us/](http://www.action.org/site/about_us/)

2 More information on these toolkits can be found at: [http://www.action.org/site/get_involved/advocacy_toolkits/](http://www.action.org/site/get_involved/advocacy_toolkits/)
It also offers a number of media toolkits including:

- 10 days when TB should be especially newsworthy
- 10 ways of engaging with the media
- 10 tips for preparing an effective news release.

Advanced toolkits for experienced advocates include:

- cultivating champions
- advocacy planning techniques
- TB control report cards.

**Organisation: International HIV/AIDS Alliance and the International Council of AIDS Service Organizations**

The International HIV/AIDS Alliance and the International Council of AIDS Service Organizations promote advocacy as a systematic means of reaching and influencing people and organisations in power to create an environment which protects the rights, health and welfare of everyone, both HIV positive and negative [25].

The International Council of AIDS Service Organisations have developed *Advocacy in Action – A toolkit to support NGOs and CBOs Responding to HIV/AIDS*. The toolkit can be used by people and organisations with different levels of advocacy experience. The toolkit includes Advocacy in Action cards with activities and information to develop practical advocacy skills in the areas of:

- analysing and influencing legislation or policies
- preparing a briefing note or position paper
- working from inside the system
- lobbying or face-to-face meetings
- writing and delivering a presentation
- persuading through drama
- writing and using a press release
- carrying out a media interview
- preparing a press conference [25].

**Organisation: World Health Organization**

In 2007 the World Health Organization published: *STOP The Global Epidemic of Chronic Disease. A practical guide to successful advocacy* [26]. The toolkit was developed in response to ‘the global epidemic’ of chronic disease and advocacy was described as, ‘essential to help to set the record straight and spur action at all levels’ [26].

The toolkit is designed to be used by a wide range of potential advocates including politicians, NGOs, healthcare professionals, journalists, patients and members of the public. Although the remit of ‘chronic disease’ is wide and includes a diversity of specific conditions and illnesses such as cardiovascular disease, cancer, chronic respiratory disease and diabetes, the strategies included in the toolkit are relevant across the spectrum. Interestingly, WHO also cite the relevance of the toolkit beyond chronic disease itself, ‘although this handbook focuses on chronic disease prevention and control, the underlying principles for effective advocacy that are described can be successfully applied to other health topics such as health promotion’ [26] and offer a guide to develop strategies tailored to specific circumstances.

The World Health Organization identifies the seven steps to developing a tailored advocacy strategy as:

- define the situation
- establish your goal and objectives
- identify your target audiences
- develop key messages to influence your advocacy plan
- develop and implementing your advocacy plan
- engage media interest
- monitoring, evaluation and useful tools.

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For each of these steps WHO offers supporting information, tools and imagery including information sheets, posters, policy briefings, packaged media features, photo stories and the texts of the Bangkok Charter for Health Promotion in a Globalized World, the WHO Framework Convention on Tobacco Control and the WHO Global Strategy on Diet. The toolkit also contains CD-DVD tools including: a video on chronic disease, technical papers, regional-specific and country-specific information sheets and a slide presentation of Preventing chronic diseases: a vital investment. The key point and messages of the WHO’s Preventing chronic diseases – a vital investment is also available in the toolkit and advocates are encouraged to adapt them to their own circumstances\textsuperscript{1} [26].

**Organisation: International Diabetes Federation**

The International Diabetes Federation (IDF) presents its advocacy guide\textsuperscript{2} with a statement of conviction:

we know the power of political advocacy; we have seen it work. In 2006, thanks to the campaigning efforts of the IDF’s member associations and the global diabetes community, we persuaded the UN to pass the landmark Resolution 61/225 recognising the impact of diabetes and prompting government action to improve support for people with the disease. With coordinated action at all levels we can make our voices heard\textsuperscript{27}.

The guide to advocacy and campaigning is sectioned into the following areas:

- Establish goals: ‘effective advocacy activities start with clear goals’. This section lists potential goals.
- Identify your target audience: ‘identifying key audiences and the influencers who can drive your agenda forward effectively and efficiently is vital to campaigning’. This section lists potential decision makers and potential influencers.
- Use key messages: ‘delivering powerful communications means understanding your audience’. This section lists some rules for key messages including illustrating messages with human interest case studies or success stories and use of facts and statistics that mean something to the audience.
- Work in partnerships: ‘establishing partnerships with like-minded NGOs, academia, the private sector and other organisations is often an effective way to spread your messages and reach a wider audience’. This section gives examples of alliances at regional and local level.
- Engage the media: ‘working with the media is a cost-effective, powerful way of communicating your messages. And professionally executed media plans are the most likely to reap media coverage’. The section outlines the characteristics of a good press release as being timely, providing contact numbers for follow-up information and looking and feeling like a news story and being relevant to the specific readership.
- Other activities to include: making presentations, organising events and participating in conferences\textsuperscript{27}.

The toolkit also provides a list of resources including:

- sample letters, press releases and briefings
- downloadable media – Powerpoint presentations, podcasts and videos
- a check list for advocacy for the UN Summit
- global and regionally-specific messages and sound bites
- IDF’s Charter of Rights and Responsibilities of People with Diabetes
- the Non-Communicable Diseases Alliance’s Proposed Outcomes Document.

The resource of key messages and sound bites contains both global and region specific messages, for example it contains messages and sound bites for Europe and for the Middle East and North Africa.

The levels of overlap between the toolkits suggest a common base of core tools for effective advocacy across different topic areas. The World Health Organization makes this commonality explicit and suggests that its toolkit is adaptable to conditions other than chronic diseases and to wider health promotion efforts. Considering these tools against the strategies identified by Freudenberg et al, [2] a consistency is, once again, apparent. Interestingly though, the strategy of public protest was a frequently used strategy in the campaigns, whereas this tactic was not included in the toolkits.

\textsuperscript{2} International Diabetes Federation advocacy guide available here: http://www.idf.org/advocacy-toolkit [27].
Examples of effective approaches – TB, HIV/AIDS and measles

An additional, specific literature search was conducted to identify examples of evaluated initiatives in health advocacy that focused on the communicable diseases of TB, HIV and measles. These diseases were selected because of their particular relevance in the European context. Some details of initiatives relating to measles were sourced although these did not include evaluations. The search identified a report of country-level good practice examples under the 'Stop TB Partnership’ initiatives [28]. Interestingly, many of the interventions also encompassed HIV/AIDS reflecting the high co-morbidity between the two diseases. Individuals with HIV are estimated to be between 20–37 times more likely to develop TB than people without HIV, and TB is a major cause of morbidity and mortality among people living with HIV.

World Health Organization

Tuberculosis has been described as an 'ideal laboratory' in which to test the efficacy of advocacy strategies:

- unlike tobacco, tuberculosis advocacy is free from unpredictable human adversaries which will attempt to sabotage every good effort. Unlike AIDS, tuberculosis advocacy is not potentially complicated by moral codes in some countries. Unlike malaria, tuberculosis surveillance is robust enough to attempt to establish causal relationships between advocacy efforts and their impact against the disease [29].

In 2005 the World Health Organization launched the 'Stop TB strategy' which has the goal of dramatically reducing the global burden of TB by 2015 [28]. At the strategy’s core is the Directly Observed Treatment Short Course (DOTS), which comprised five components:

- sustained political and financial commitment
- diagnosis by quality ensured sputum-smear microscopy
- standardised short-course anti-TB treatment (SCC) given under direct and supportive observation (DOT)
- a regular, uninterrupted supply of high quality anti-TB drugs
- standardised recording and reporting.

Building on this strategy, six new components have recently been added:

- pursue high-quality DOTS expansion and enhancement
- address TB-HIV, multidrug-resistant TB and the needs of poor and vulnerable populations
- contribute to health system strengthening based on primary health care
- engage all care providers
- empower people with TB and communities through partnership
- enable and promote research.

Advocacy is cited as having a role in the last of these components but it is a major element of the empowerment component wherein the three activities of advocacy, communication and social mobilisation (ACSM) are grouped together as ‘an essential strategic component of TB control’ [28]. Advocacy is categorised into three types by WHO and descriptions of each type are given:

- policy advocacy: informs senior politicians and administrators how an issue will affect the country and outlines actions to take to improve laws and policies
- programme advocacy: targets opinion leaders at the community level on the need for local action
- media advocacy: validates the relevance of a subject, puts issues on the public agenda and encourages the media to cover TB-related topics regularly and in a responsible manner so as to raise awareness of possible solutions and problems.

The World Health Organization produces handbooks and guides to support ACSM activities. In 2010, WHO published a collection of case studies of good practice in which ACSM interventions, ‘have contributed to a positive outcome of TB control activities directed to a range of audiences and settings’ [28].

The ACSM sub-group asked implementers of ACSM initiatives to submit their intervention for consideration as an example of good practice. Thirty-five implementers submitted a case study in which they described: the TB situation in their area, the population served, their ACSM objectives and activities and the results to date. From the thirty-five submissions, sixteen examples of good practice were included in the document Advocacy, Communication and Social Mobilisation for Tuberculosis Control. Collection of country-level good practices. Three of the 16 interventions took place in Europe – Romania, Moldova and Ukraine - and will be considered below.

In line with WHO policy, the interventions were developed and carried out in partnership with local organisations and addressed local challenges. Two of the interventions lasted for two years and one lasted for four years.
In Romania, the intervention targeted the Roma population who are believed to experience levels of TB between two and seven times higher than that of the general public in Romania. The reason for this disproportionate burden includes discrimination against the Roma by both health care providers and the general public, the Romas’ difficulty in complying with the bureaucratic process required to access treatments, and the substandard living conditions in which many of the Roma live.

The focus of the Moldovan intervention was the general public and health workers because it had been established that there existed a severe lack of understanding about TB among both these groups. But a more specific focus was also vulnerable groups such as people who inject drugs and people living with HIV/AIDS (PLWHA).

As with the previous two examples, the focus of the Ukrainian intervention included PLWHA. Tuberculosis in itself is a major public health problem in the Ukraine, but this is exacerbated by the ‘remarkably high rates of drug resistance and the rapidly growing HIV epidemic’ [28].

The aim of the interventions reflected the needs of the population and the environment in which the intervention was situated.

The Romanian intervention focused on capacity building through training Roma peer educators to:

- improve TB-related knowledge
- enhance community members’ ability to surmount the legal obstacles to accessing public health services
- develop the capacity for community-led advocacy initiatives by building skills, mobilising stakeholders and devising advocacy strategies that create a policy environment conducive to promoting Roma health.

The project also worked to promote more receptivity towards the Roma (who often face discrimination throughout society) by doctors and nurses, in order to improve client-provider relations. The success of the project was described using indicators that included the numbers of Roma who attended the 480 intensive three-month community education sessions and the number of Roma who accessed diagnostic services, accompanied in most instances by trained Roma supporters, and the number of patients who were diagnosed as having TB as a result of the intervention.

The Moldovan intervention measured success by the changes in levels of public awareness of TB and the availability of free treatment for TB. At the end of the intervention:

- the percentage of surveyed people who understood that coughing is a leading cause of transmission increased by 16.4 percentage points to 78.2%
- the proportion of Moldovans who understood that TB can be treated more than trebled, rising from 12.9% of those surveyed to 39.3%
- the number of people who believed that the disease was untreatable or were unsure on the question dropped from 28.4% to only 11.6%
- the rise in public consciousness of TB and its effects and causes directly contributed to the formation and official registration of Speranta Terrei, the country’s only NGO comprised of former TB patients. The group’s work with current patients and their relatives has been highly successful in advancing the cause of a patient-centred approach to TB treatment.

The Ukrainian intervention sought to improve the quality of DOTS and also to establish a patient-oriented approach to providing TB and TB/HIV services among the most vulnerable groups [28]. The stigmatisation experienced by both TB and HIV/AIDS patients from society in general, but also healthcare providers in particular, contributed to a treatment default rate in excess of 20% in some regions. At evaluation, the numbers were reported as being small but positive with the default rate in the intervention regions dropping to almost zero. The advocacy programme was deemed very successful, not least for its success in securing funding from local budgets for ongoing support of the Ukraine Red Cross Society.

**European Centre for Disease Prevention and Control**

As discussed above, the World Health Organization has a number of initiatives in Europe. A European specific strategy to tackle TB - the Framework Action Plan to Fight Tuberculosis in the European Union - was launched by ECDC in 2008. This Framework largely reflects the WHO strategy but does not contain any references to advocacy or the role of advocates. Tuberculosis in Europe is concentrated disproportionately in the more vulnerable and hard to reach groups.

TB is found increasingly among vulnerable populations. These include immigrants from other countries with a high TB incidence, prisoners, HIV-seropositive persons, residents of hospital wards, nursing homes and homeless shelters, the elderly and household contacts of recent TB cases. The most vulnerable and excluded groups are the ones that carry the most significant burden of disease and which have the poorest access to services [30].
ACTION: Advocacy to Control Tuberculosis Internationally

ACTION is an international partnership of advocates that use targeted advocacy in donor and high tuberculosis burden countries. ACTION argues that the similarities which appear apparent in advocacy strategies, such as the use of media, advocacy materials and message development, can serve to somewhat mask the key importance of distinguishing the audience that the strategy seeks to target. Thus, advocacy strategies either seek to impact on social agendas as an indirect means to engage and inform the relevant policy makers or use direct means to engage and inform the relevant policy makers personally. ACTION further desegregates direct and indirect advocacy and provides advocacy examples of each, some of which are reproduced below:

- **indirect**
  - research advocacy: Global Plan to Stop TB; Commission on Macroeconomics of Health
  - coalition advocacy: Global Health Council; Stop TB Partnership
  - mass advocacy: ONE Campaign; Make Poverty History

- **direct**
  - bureaucratic advocacy: United Nations General Assembly Special Session on HIV/AIDS; World Health Assembly
  - protest advocacy: ACT-UP; TAC
  - legal advocacy: no example given

In 2007 ACTION published *Best Practices for Advocacy* [29] a compilation of tools, tactics and strategies used in their campaigns with the stated intention that, ‘these best practices will provide a model for replication globally and usefully inform other advocacy initiatives to increase political will to address TB and other vital global health issues’ [29].

Measles

In 2002 the World Health Organization Regional Office for Europe commenced the implementation of a strategic plan which aimed to eliminate measles and prevent congenital rubella by 2010 [31]. The strategy identified the key areas for action as: national policy development, surveillance, immunisation quality and safety, coordination and policy, communication/advocacy and a certification process. The communication/advocacy made particular reference to Member States that had experienced adverse publicity about immunisation urging them to have approved communication plans ready with which to counter negative publicity and provide specific, targeted, high quality information to both healthcare providers and the public. Adverse publicity is identified by ECDC as one of a number of challenges to effective programmes of vaccination; other challenges range from, ‘lack of information to false perceptions regarding the benefit-risk ratio of the vaccination, to active opposition due to personal or religious beliefs or societal expectations’ [32].

A regional advocacy strategy, evidence-based and with effective advocacy approaches that were sensitive to different regional and sub-regional issues, was to be developed by WHO. In 2011, EU health ministers acknowledged that rather than celebrating the reduction in the incidence of measles, they were witnessing a ‘dangerous re-emergence’ of the disease [33]. Dr Marc Sprenger, ECDC Director, reported to the EU that only 17 EU Member States have reached the 95% level of vaccination for one dose of the Measles, Mumps and Rubella vaccine; coverage for two doses of the vaccine is suboptimal in almost all the EU countries [34]. Interestingly, within the World Health Organization’s European Region, it is the EU Member States that have the lowest vaccination rates and the highest burden of the disease and WHO reported that 96% of the measles cases in the 2009 data were located in western Europe [34].

In response to the looming crisis, in June 2011, the EU announced, ‘plans to monitor the growing health risk of vaccine-scepticism and to produce a communications strategy to advocate for immunization’ [35]. The campaign will represent an EU wide approach to developing a ‘public relations toolbox’ so as to provide clear, factual, evidence-based information to people who are critical of vaccinations.

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¹ World Health Organization European Immunization Week website. Available at: [http://eiw.euro.who.int/profiles/blogs/good-news-week-for](http://eiw.euro.who.int/profiles/blogs/good-news-week-for)
European Immunisation Week, coordinated by the World Health Organization Regional Office for Europe, is an annual advocacy initiative to raise awareness with a view to increasing all vaccination rates and with a particular focus on activities to reach vulnerable populations. Countries of the WHO European Region implemented a variety of activities including media events, political debates, training for health professionals, art competitions, exhibitions and workshops for parents. Most countries targeted vulnerable groups and one third undertook vaccinations among these groups. The 2009 campaign was evaluated through an online survey of ‘focal points’ in the thirty-seven participating European countries, and through an assessment of online activities by an external consultant. The 2009 Immunisation Week was innovative as it utilised the internet and social networking sites for the first time, in order to, ‘counter misinformation about vaccination spread via the Internet, and sought to use the media that have been dominated by anti-vaccination groups’ [36].

An animated video1, designed to be ‘memorable and provocative’, was uploaded onto YouTube.

The evaluation noted that:

- During its first two weeks on YouTube, the video had 10 000 viewers and became the most viewed WHO online video.
- The video was highlighted on YouTube’s ‘most viewed’ and ‘most watched’ categories on April 24 2009.
- The video generated in excess of 4 000 visits to the European Immunisation Week campaign website which was a sevenfold increase on the number of visits during the campaign of the previous year.
- The video also generated social media commenting through YouTube and Twitter.
- It gave rise to online discussions and was highlighted on more than 17 blogs across Europe.
- The video and linked website continued to raise awareness of European Immunisation Week and immunisation after the end of the official campaign [36].

However, some participating European countries reported that its impact was limited by it only being available in the English language and by the lack of access to computers and the internet in some settings. Other criticisms of the video included that, while it was appropriate for parents and students, it was less appropriate for health professionals. In general, the campaign was considered by 90% of the participating countries to have been a success; the barriers to a successful campaign were identified as including:

- the timing – as it overlapped with the Easter holidays
- changes of plan due to changes in government
- the emergence of the H1N1 influenza pandemic
- lack of funding.

Despite the barriers, 85% of the respondents to the evaluation survey considered that the campaign was so worthwhile that they would recommend that their country would continue to participate in European Immunisation Week [36].

In 2010, 47 European countries participated in European Immunisation Week which was run simultaneously with Vaccination Week in the Americas and in the Eastern Mediterranean region involving a total of 112 countries. The number of participating countries increased again in 2011 when 52 states participated in European Immunisation Week.

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http://www.youtube.com/watch?v=sGRs1ED_rw&feature=player_embedded
Evaluation of advocacy interventions – methodological approaches and outcomes

Evaluation of advocacy activities has been described as problematic for a number of reasons including; the range and scope of methods employed in any advocacy initiative, the length of time that an advocacy campaign may run for, the different manifestations of the campaign over this time, and the identification of the goals of the campaign. A number of sources document the methodological challenges of advocacy evaluations [37–41] with a good deal of consensus that these challenges include:

- the role of external forces and conditions
- the intricacies of public policy making
- unpredictability and complexity of advocacy interventions
- the long time frame needed for changes to occur
- attribution
- shifting strategies and milestones
- low capacity and interest in evaluation from advocacy agencies and/or grantees
- knowledge accumulation is rare.

From the perspective of policy change evaluation, Guthrie et al, [38] and O’Flynn [41] expand on a number of these challenges:

- External forces such as the political or economic environment or the effectiveness of opposition strategies can impact on the outcome. Campaigners can only be expected to do everything right that is within their own control.
- The complexity of the policy arena means that change will be nonlinear and iterative. Indeed, effective policy advocacy might involve the absence of change rather than change or the promotion of a constituency to advocate for change. The multi-component nature of advocacy also adds to its complexity.
- The long time frame required for policy change to occur means that rather than asking ‘did policy change?’ More appropriate questions would be ‘how did the grantee’s work improve the policy environment for this issue?’ Or ‘how successful was the grantee in taking the necessary steps towards policy change?’ Advocacy is more often the work of decades rather than years.
- Shifting strategies and milestones require advocacy efforts to be flexible ‘without being merely reactive or haphazard’ [38] and advocates to adjust their strategies, as necessary, to reflect the current environment. Equally, the objectives of a campaign may be forced to change over the lifetime of the campaign.
- Attribution is difficult to establish in advocacy because ‘there is no control group’ [38]. It is rarely possible to distinguish the precise contribution or effect of specific activities or players. O’Flynn suggests that a solution to this is to focus on contribution rather than attribution [41].
- Low capacity and interest in evaluation from advocacy agencies and/or grantees may result from lack of experience, expertise or resources. However, without the commitment and engagement of the advocates/grantees quality evaluation data will not be collected in a timely manner that would enhance their ongoing campaign.
- Knowledge accumulation is rare both because of lack of formal documentation but also because advocates may not wish to make their strategies public. As a result, the same lessons are being relearned during advocacy campaigns.

However, the challenges of advocacy evaluations are in themselves a compelling reason for evaluation. Evaluations can identify the significant and appropriate expectations of an initiative, the most effective strategies, and may support the development of best practices [37], serving to keep an initiative on track or, alternatively, indicate when it is advisable to adjust or adapt the advocacy strategies. Evaluation is also of great significance to the intended beneficiaries of advocacy and Whelan stressed the importance of their involvement to guard against ‘the temptation of professional lobbyists to see a ‘successful advocacy effort’ when the intended beneficiaries see nothing changing’ [39]. Mayoux stressed that only with such an inclusive approach can an evaluation be meaningful [42]. Thus, she argues that a goal of changing policy or legislation may have been achieved but that this will be of little real value if people do not know that this change has come about or if they are unable to access the legal services to vindicate their rights. This may be particularly relevant to women whose lived realities may change little despite legislative and policy changes [43]. Likewise, policy and legislative changes are only of use if they are enforced.
O’Flynn [41] stated that although the terms of reference for individual advocacy evaluations will differ, a core set of questions will be common to all evaluations:

- to what extent were the original objectives achieved? Or were they the right objectives in the first place?
- how did the objectives change and evolve throughout the advocacy project, and why?
- what impact did any change have on the lives of communities (if at all)
- what factors contributed to success or failure?
- which specific approaches worked and which did not? What should be done differently given hindsight?
- what needs to be changed in the future as a result of this evaluation? [41].

A 2007 Guide to Measuring Advocacy and Policy commissioned by the Annie E. Casey Foundation reviewed outcome categories and progress indicators from a multiplicity of sources including reports, expert interviews and relevant literature and consolidated these into, what they claim, are, ‘six distinct categories representing the essential changes in lives, community conditions, institutions and systems that result from advocacy and policy work’ [37].

These six categories comprise:

- a shift in social norms
- strengthened organisational capacity
- strengthened alliances
- strengthened base of support
- improved policies
- changes in impact.

The guide offers examples of outcomes and strategies and units of analysis for each of the six categories.

Alternatively, Coffman [44] suggests three possible outcomes that advocacy evaluation can measure: advocacy capacity, progress towards the advocacy goals and the advocacy’s impact. Most advocacy evaluations focus on more than one of these outcomes. Advocacy capacity, according to Coffman, ‘refers to the knowledge, skills and systems an organisation needs to implement and sustain effective advocacy work’ [44].

Advocacy capacity is referred to as being of ‘critical’ importance to the success of an agency’s advocacy efforts and increased advocacy capacity may be the most visible result of advocacy. Evaluation that measures progress towards the advocacy goals can usefully be carried out at points throughout the campaign to assess the extent that progress is as planned or whether adjustments to the advocacy course need to be made. Impact evaluation has traditionally sought to measure whether a causal relationship exists between an intervention and its expected outcomes [44]. However, advocacy impact intervention attends instead to one or more of the following:

- assesses the longer-term ‘big’ outcomes that precede policy change (e.g. public will, political will, shifts in social norms)
- determines whether a plausible and defensible case can be made that an advocacy effort has impacted the policy process or contributed to a policy change
- documents the long-term impact of advocacy and policy change on people’s lives (or on the environment, the economy etc.) [44].

Theory of change

Although advocacy evaluation can take place at many stages throughout the initiative and afterwards, issues of evaluation are widely recognised as playing a role in the strategic development of an initiative, particularly in the realm of theory of change.

Theory of change is increasingly being used as a strategic planning tool for advocacy and activism [39], to demonstrate that the design of an advocacy campaign is sound, and as a tool for evaluation [40]. A useful definition of theory of change is:

A set of assumptions about advocacy activities and their intended results. Theories of change include a step-by-step series of advocacy activities, typically linked in a flow chart to the desired results. Theories of change help to plan advocacy efforts and provide a basis for evaluating them in real time, indicating whether the intended results are occurring or if there is a need to modify the advocacy strategy [45].

A theory of change makes explicit the anticipated relationship between actions and outcomes and provides an explanation of the assumptions and belief systems that underpin the initiative [37]. The use of a theory of change necessitates making explicit the underlying assumptions that underpin the belief that the activities to be engaged in will achieve named outcomes as it develops along identified pathways. It is distinguished from a mission statement by its precision; all the steps of the pathway are detailed and identified and the resulting ‘blueprint’ offers a coherent framework for evaluation [45].
A theory of change may be as short as a paragraph of text [40] or may be depicted in a visual map and the value of the process is to provide:

- a clear testable theory about how change will occur, which gives a framework for monitoring and evaluation and provides the basis for accountability and learning
- a visual representation of the change and how it will come about
- a blueprint for evaluation with measurable indicators of success identified
- an agreement among stakeholders about what defines success and what it takes to get there
- a powerful communication tool to capture the complexity of the initiative.

As part of the theory of change, interim outcomes will be identified and this is of particular importance in an advocacy campaign which may be of very long duration. The International Council of AIDS Service Organisations identify that the emphasis of advocacy evaluations is increasingly on the changes made towards goals rather than the attainment of the goals themselves [25]. Coffman argues, ‘with advocacy, it is important not to assign second-class status to outcomes other than policy change’ [44].

A number of guides and tools are available offering to support organisations and groups to develop a theory of change for their initiative or intervention, including the following:

- The Aspen Institute’s Advocacy Planning and Evaluation Programme offer practically focused web-based tools to assist donors and advocatesi [45]
- The Anne E Casey foundation and Organisational Research Services have developed Getting Started: A self-administered Guide to theory of change development and advocacy evaluation planning 2009. This offers methods and tools for advocacy organisations and ‘provides a template for advocates to walk through development of a theory of change outcome map’ [37]
- The International Network on Strategic Philanthropy offers a toolii to assist people to create a theory of change to map out programmes or initiatives in strategic philanthropy [46].

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i Continuous progress tool. The Aspen Institute's Advocacy Planning and Evaluation Programme. Available at: http://fp.continuousprogress.org/about

Conclusions

Advocacy has been identified as a key strategy for health promotion and public health and a powerful tool to promote actions on the social determinants of health [13]. Notwithstanding its acknowledged importance, scant evidence has been published about public health advocacy campaigns and within the existing literature, communicable disease is rarely discussed. This review identified and considered a range of sources of evaluated health advocacy interventions, models and toolkits, and examples of best practice in the wider health advocacy arena in order to inform the development of strategies and resources focusing on communicable disease.

A review of public health advocacy campaigns by Freudenberg et al. [2] identified common and effective strategies most of which were consistent with those proposed in other models. This consensus suggests a firm foundation upon which to develop a common framework for public health advocacy. Freudenberg et al's observations about the trend to frame campaigns around social justice and the importance of social context to the success of a campaign may be particularly instructive for designers of new initiatives.

The review of a number of guides and toolkits developed by advocacy organisations to provide highly professional resources for use by experienced and inexperienced advocates, identified a considerable level of consensus about core components. The availability of these resources facilitates the recruitment of volunteer advocates and ensures that they direct their energies effectively and deliver an accurate and timely message.

The methodological challenges of evaluating advocacy initiatives provide a forceful argument for adopting a more considered and systematic approach to such evaluations. Recent developments have strengthened the knowledge base for such evaluations and the recommended utilisation of a theory of change benefits the development of an advocacy initiative by making explicit the intended relationship between actions and outcomes.

Notwithstanding the lack of evidence of health advocacy campaigns for communicable disease, there is both an emerging knowledge and resource base which will provide a useful springboard from which such campaigns may be developed in the future.

Identification of gaps in the evidence and recommendations for further research

Health advocacy for communicable diseases is clearly still at a nascent stage and the current evidence base is very underdeveloped. The duration and complexity of public health advocacy campaigns and initiatives makes the need for theory-based evidence imperative. The shared consensus in the literature about core components of health advocacy initiatives and the existence of templates and toolkits in the area means that foundations do exist on which to develop. To this end, further research and action is needed in the following areas:

- The core components identified in existing advocacy models and strategies should be utilised in the further development of public health advocacy strategies.
- The existing toolkits provide useful templates to progress health advocacy strategies for communicable diseases in Europe.
- A pan-European template for public health advocacy should be developed which could then be tailored to the needs of individual countries. The development of accessible user friendly web-based tools would enhance this resource.
- All health advocacy campaigns targeting communicable diseases should incorporate a systematic evaluation component utilising a theory of change approach.
- A systematic approach to the development of an evidence base on effective public health advocacy strategies in Europe should be prioritised.
References


44. Coffman J. Overview of current health evaluation practice: Center for Evaluation Innovation 2009
