



Health Research
Charities Ireland

Evidence for Advocacy: A Practical Guide

Guidance on the generation and use of
evidence in charity advocacy campaigns

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About the Health Research Charities Ireland (HRCI)

Health Research Charities Ireland (formally the Medical Research Charities Group) is the national umbrella organisation of charities active in medical and health research, together representing over 1 million Irish patients. Through support and advocacy, we represent the joint interests of charities working to improve health and prevent illness through research. We also run the Irish Health Research Forum, bringing together all stakeholders to improve health research in Ireland. It is our core belief that today's health research is tomorrow's healthcare.

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'Evidence can help us to really understand an issue, inform us about things we were previously blind to and lead us to the best solutions.'

Foreword

Patient-focused charities and other community organisations increasingly seek to be guided in their activities by evidence. In parallel, policy makers now regularly seek evidence from those who are advocating for improved services and access to care. Evidence can help us to really understand an issue, inform us about things we were previously blind to and lead us to the best solutions. Although the use of data and evidence to support advocacy is not a new concept, it can be a challenging environment to navigate and there is limited guidance available.

On 30 May 2019, a group of patient-focused organisations and other interested parties attended Health Research Charities Ireland (at the time called the Medical Research Charities Group) 'Evidence for Advocacy' seminar. They heard diverse perspectives from experts in research, policy and public relations (PR) and were also presented with case studies from a number of charities sharing refreshingly honest accounts of their experiences. By focusing on advocacy through a research lens, the event highlighted the power of taking an evidence-informed approach to support advocacy campaigns and to guide efforts to improve health.

This practical guide follows on from that seminar and draws on the information presented by the speakers, contributions from the floor, as well as the expertise of the authors and Health Research Charities Ireland (HRCI). We are very grateful to all who contributed.

The research-focused members of HRCI are well-placed to use evidence to strengthen their advocacy campaigns. They and other charities have a tremendously important role to play in this space because of where they sit in society; often acting as a lynchpin between the communities they represent, healthcare and other service providers, policy makers and researchers. That, together with their long-demonstrated traits of innovation and persistence on behalf of the communities they work for, mean that they will have an increasingly important role in evidence-based healthcare in the years to come.



Dr Avril Kennan
CEO, Health Research Charities Ireland



Introduction

Effective advocacy¹ is strengthened by the gathering and presentation of evidence to make a case for change. That may be in the pursuit of changes to service design and delivery, new public policy, increased public awareness of an issue or funding for your organisation to continue or expand its work.

Evidence can come in many forms, but increasingly health charities are looking to conduct research themselves, to better understand the needs of their community or to support their advocacy work. This can bring with it a number of challenges, depending on the size of the organisation and the time and resources available. Amongst the questions charities grapple with are:

- **What type and level of evidence will be appropriate to make our case?**
- **What research can we effectively undertake ourselves and when should we partner with an external research group?**
- **How can we present the evidence we generate in the best way, so that it has impact for the populations we support?**

This guide outlines the key strategies and approaches to gathering and using evidence for advocacy purposes. Its three core sections focus on the gathering and generation of evidence, the use of evidence to influence policy and the role of the media in evidence-based campaigns.

While it is primarily focused on charities and other civil society organisations working in the area of health and social care, we hope that those working in other areas of advocacy will also find it useful. Equally, while it has been written from an Irish perspective, most of the content is relevant for those operating in other countries.

¹ In the context of this guide, we are using the term advocacy to refer to campaigns and activities aiming to influence policy and practice decisions at national and institutional levels, in the area of health.

Gathering and generating evidence

Where to start

Before you initiate the process of gathering evidence or conducting research, it is important to be very clear about what you are trying to achieve. In many cases, the aim will be to guide organisational strategy or to provide an evidence base for your advocacy campaigns. However, it may also be the case that you are undertaking research specifically to generate awareness or publicity about a cause. Your motivation will naturally inform decisions regarding the scale of the research required and the rigour with which it is undertaken. Once you have identified and defined the issue, you can set about planning your approach.

Some initial questions to consider:

- What are you trying to achieve through advocacy?
- Will your aims be strengthened by evidence?
- Who will you need to speak with to ensure you are getting all perspectives?
- What existing evidence is available?
- If new research is required, how will you undertake it?
- If the research will involve the population you support as participants, will there be benefits to them and is there a risk of over-burdening them?
- Do you have time limitations?
- What resources are available to you?
- Is there a possibility to have research funded through a research funding scheme?
- Are you prepared for the possibility that the final results may not support your advocacy campaign?

Considering existing evidence

Firstly, look at the existing evidence of relevance to your advocacy campaign. Evidence can come in many different formats and from various sources; we are taking an inclusive definition of it, to include any form of robust data that answers a relevant question. It is often, but not always, generated through research methodologies. It may be quantitative (concerned with counting and measuring) or qualitative (captured from opinions, experiences and observations), neither of which is superior to the other. It may be data you have generated through a local research project or international evidence pointing to best practice. Some examples of evidence include:

- Experimental research findings – qualitative or quantitative
- Systematic or rapid reviews and meta analyses
- National or international policy or programme evaluations
- Existing statistics – data from patient registries, census data, OECD figures etc.
- Consensus expert opinion
- Stakeholder consultations
- Testimonials or case studies
- Costings of policy options

See Appendix 1 for useful sources of evidence for Irish organisations.

The type of evidence you require will depend on the policy or practice you are trying to influence. In whatever form it comes however, good evidence should be objective, credible, relevant and verifiable. Peer reviewed research adds an element of comfort that it is of good quality, as do multiple sources of evidence pointing to the same outcome. As you consider the 'off the shelf' evidence, be mindful of the common pitfall of cherry-picking evidence that fits your existing beliefs².

Once you have a clear picture of what existing evidence is available, you can better identify where the gaps are and what your focus should be

² For more on this topic and other in-depth information on using evidence in all of your organisations activities, see: <https://www.alliance4usefulevidence.org/publication/using-research-evidence-a-practice-guide-january-2016/>

if you do need to conduct new research. This will help you to be more concise in developing your research question and in deciding on your project plan and methodology.

Planning new research

If, as is the case for many charities, you are well connected to the relevant stakeholders, you will be in a strong position to instigate new research. You are likely to have a good understanding of the challenges that your community is facing and to know how to reach the relevant participants.

There are a number of considerations before you begin however. It is important to have a well-defined project plan to cover all relevant elements of the research process. Increasingly, health research charities employ individuals with research backgrounds but, even without such a resource, it is possible to gather or undertake your own research, for example, through the use of online survey tools. However, as opposed to simply going with the easiest research option, it is important to thoroughly consider what type of research makes most sense for the evidence you need. For example, the use of ethnography (where researchers observe a situation from the subjects' perspective) might give richer data than a survey alone. Taking the following steps should aid your planning:

1. Become as **familiar as possible with the issue(s) in question**, through discussions with all stakeholders.
2. Assess and prioritise the value of **existing evidence**.
3. Aim to **include the communities that the outcomes of the research will impact**, from the earliest planning phases. There are many excellent patient and public involvement (PPI) resources to guide you in this, including a practical guide on developing a PPI strategy from HRCI³.
4. Depending on the scale of the project, consider establishing a **steering committee**, with representation from all key stakeholders and defined terms of reference.
5. Develop a **well-designed research question** and ensure that the project plan will lead to the answering of this question.
6. Identify your **research participants**, for example, patients, parents, carers, teachers, siblings, healthcare professionals, budget holders.

³ Developing a PPI Strategy: A Guide. Health Research Charities Ireland (Medical Research Charities Group), 2018. <http://bit.ly/PPIStrategyGuide>

7. Give consideration to all **ethical matters** arising.
8. Identify potential **collaborators**.
9. Prepare a **budget** and consider funding options.
10. Plan for how you will **evaluate the success** of your research project and its impact on your advocacy.

Finding a research partner

You may decide that partnering with an academic⁴ research group or market research company is the best way to conduct your research and achieve your goal. The involvement of external researchers can add credibility to the research findings as they have no conflict of interest in the outcomes. Market research companies are effective if you wish to answer a very specific question in a short time frame but can be an expensive approach. Academic research tends to build on a body of evidence that already exists, can be broader in scope and is subject to critical review but it involves longer timeframes.

In the case of seeking an academic partner, you will ideally want to identify an interested researcher or research team that are leaders in the type of research you wish to conduct. It is a good time to do this as the academic community is increasingly looking to engage with wider civil society. It is not essential but can be helpful if the researchers are in your geographical area. Trying to find such a partner can sometimes appear daunting but here are some approaches you might take:

- Ask other **research-focused charities, academics or research funding agencies** (who have excellent knowledge of many research groups) if they can recommend someone.
- Work with **dedicated facilitators of patient and public involvement or engaged research**⁵.
- Undertake an advanced search in a publication database such as PubMed, which allows you to search by author affiliation as well as research key words. For example, a PubMed search for the terms 'Ireland' and 'qualitative' yields over 2,000 results.

4 We are using the term 'academic' loosely throughout this document, to refer to any researcher linked to an academic institution, be they junior or senior, based in a university, college or a hospital etc.

5 In the Irish context, these include the University-based PPI Ignite programmes and Campus Engage.

- Look through the **references section of relevant scientific publications**.
- **Invite tenders** from researchers. Among the information provided in the tender document should be the research requirements, the expected layout of the final report and the information required from applicants. You should also state how received tenders will be evaluated.

Working with a research partner

Having identified a research group who are interested in working with you and as you start to make plans, there are many things to consider and address. Many charities have run into issues in partnering with researchers due to differences in expectations and approaches. The following tips will help you to avoid any difficulties:

- Have a clear brief and goal in mind and share that with the research team. Equally, ensure you understand the perspective and goals of the research team, whose needs from the project are likely to be different from yours (for example, their primary goal might be publication and your primary goal might be patient impact). It is good practice to lay out the respective roles and expectations of both partners in writing at the outset (for example, who will review and be an author on any publication). You should also identify a lead point of contact in each organisation.
- You should invest time to ensure that the research team understand the perspectives of your organisation and the community you represent. There may be challenges for the community that they will need to be sensitive to (for example, patients and families living with difficult conditions, bereaved families, families facing trauma).
- While your organisation's involvement in the project will be a valuable form of PPI, you should also encourage the involvement of members of the community that the research will focus on, from the earliest stages of planning.

- You will also need to consider whether members of the community you represent will be willing to be participants in the research, if required. Give thought as to how to make it as easy as possible for them (for example, you could ask the researchers to conduct interviews in the participants' homes or a place of their choosing).
- The researcher partner will need to apply for ethical approval from their institution. Ensure that you are fully familiar with the details and conditions of that approval.
- Research takes time and money and you should aim to ensure that it is appropriately resourced. It may be possible to apply to a funding agency for a grant⁶. If this option is open to you, you will need to consider how the timelines for the grant application process will sit with your timelines. If the research team are applying for funding for the research, aim to ensure that your organisation's costs are built into the application. Unfortunately, this is not a given and can present challenges when it doesn't happen.
- If the research team are leading on a funding application (mandated by many research funding schemes), aim to be a partner on the application, or at least a collaborator. This helps to ensure that you retain some control over the direction the project takes.
- If necessary, consider how any intellectual property (IP) emerging from the project will be managed.⁷
- Academics are often working on multiple projects and have many pressures on their time. Therefore, the research should be subject to milestones and deadlines. These may be imposed by a funding organisation but, if you are commissioning and funding the research directly, it is important to ensure that legal agreements are in place, laying out the terms and conditions of the funding. Even if, or perhaps especially if, there is not a particular funding stream available, it is still important to agree on timeframes for the project.

6 An example of a relevant research funding scheme is the HRCI/HRB Joint Funding Scheme. https://www.mrcg.ie/go/mrcg_hrb_joint_funding_scheme

7 For guidance on the management of IP and knowledge transfer in charity-funded research, see this HRCI guide: <https://www.mrcg.ie/go/publications/recommendations>

- Know your strengths and be confident in your research partner's strengths to make decisions on issues that are not your area of expertise. While you might work in partnership on the research questions and how the research will be undertaken, it is important to refrain from having (or in any way appearing to have) an influence on the research findings, in order to maintain the legitimacy and independence of the research findings.
- Understand that partnerships across sectors take time to build. Communication and relationship-building are key. Time invested is likely to reap rewards beyond the lifespan of the initial project.

For additional guidance on partnering with higher education institutes more broadly, see this guide from Campus Engage.⁸

⁸ Campus Community Partnerships. Campus Engage. <http://www.campusengage.ie/wp-content/uploads/2018/12/Campus-Community-Partnerships-WEB.pdf>

Thinking ahead to how you will communicate your research

Although often thought of as something that happens at the end of a project or upon publication of the research, how you will communicate your findings should be considered from the outset. This includes asking some foundational questions as to what your communication objectives are and who your target audiences will be. The subsequent sections offer some guidance on how to present and effectively communicate your evidence-based campaign.



Examples of advocacy campaigns that can be strengthened by evidence

There are numerous examples of health-related advocacy campaigns undertaken by charities and community organisations, almost all of which benefit, or would benefit, from some form of evidence. Examples include:

- 1 Making the case for equality in the provision of healthcare for a particular condition.** Evidence to support this might include evidence from a national research institute on geographical inequalities in healthcare supply, data from a patient registry on the number and location of people affected, along with qualitative research data from focus groups on the impact of healthcare inequalities.
- 2 Making the case for increased nursing support for children with a debilitating condition.** Evidence to support this might include data from a longitudinal study on the condition, case studies of children before and after implementation of a pilot nursing service, together with qualitative data from interviews with families on the impact it has on their quality of life.
- 3 Making the case for State reimbursement of an expensive medicine.** Evidence to support this might include data from surveys on the impact of the medicine on daily symptoms of importance to patients and health economic data on the cost of not treating the condition.

For more examples of the use of evidence by charities, see The Alliance for Useful Evidence publication 'Evidence for Good'.⁹

Using evidence to inform policy

Public policy can be loosely described as a system of regulations, laws and formal approaches, concerning a given topic, which are used to inform actions and funding allocations by agents of the State. In recent years there has been a noticeable move towards using evidence to inform policy. Therefore, as you advocate for changes to policy there is a strong need to present evidence to support your case. Activities undertaken to influence policy and political decisions are often referred to as public affairs (although the term can also include broader activities). While we have focused this guide on efforts to change policy, sometimes it may be practice that you wish to impact. Of the two, changes to practice can be easier to achieve but the principles outlined here still apply.

Where healthcare policy originates

Whether you are trying to influence changes at a local or a national level, it is helpful to become familiar with where policy originates, in order to identify the most effective advocacy route to take.

Public sources: healthcare policy is often developed by government agencies and can be in the form of laws, regulations and other standards. It is influenced by evidence, politics, interest groups, economics, demographics etc. Examples of relevant policies include those relating to the recruitment of health care professionals and national health issues such as obesity.

Organisational sources: policy can be developed by healthcare providers to govern work place practices. It can be influenced by wider policy but also the needs of service users, staff and other stakeholders. Examples of relevant policies include those relating to patient safety and the management of hospital waiting lists.

Professional sources: policy can also be developed by accrediting and professional organisations that establish guidelines and evidence-based recommendations for healthcare delivery. An example of this type of policy is clinical practice guidelines for diabetes.¹⁰

¹⁰ Adapted from 'Healthcare Policy: Where it comes from and how to change it'. John T. Brinkmann, 2018. <https://opedge.com/Articles/ViewArticle/2018-01-01/healthcare-policy-where-it-comes-from-and-how-to-change-it>

The policy development life cycle

Evidence-informed decision-making for health policy is focused on more than clinical outcomes. It requires a broader lens and takes into account non-clinical factors relating to political perspectives, economics, health equity, acceptability and human rights. Ideally, it is also developed with input from a wide range of fields including economics, sociology, psychology, demography, political science, management sciences etc.

Evidence-informed decision-making uses the best available evidence (which has been developed systematically and transparently) at each stage of the policy development life cycle (see figure 1). It is important to think about the problem you are trying to find a solution to in the context of this cycle. Many patient-focused charities are well-placed to contribute both clinical and non-clinical evidence to help shape and refine policy.

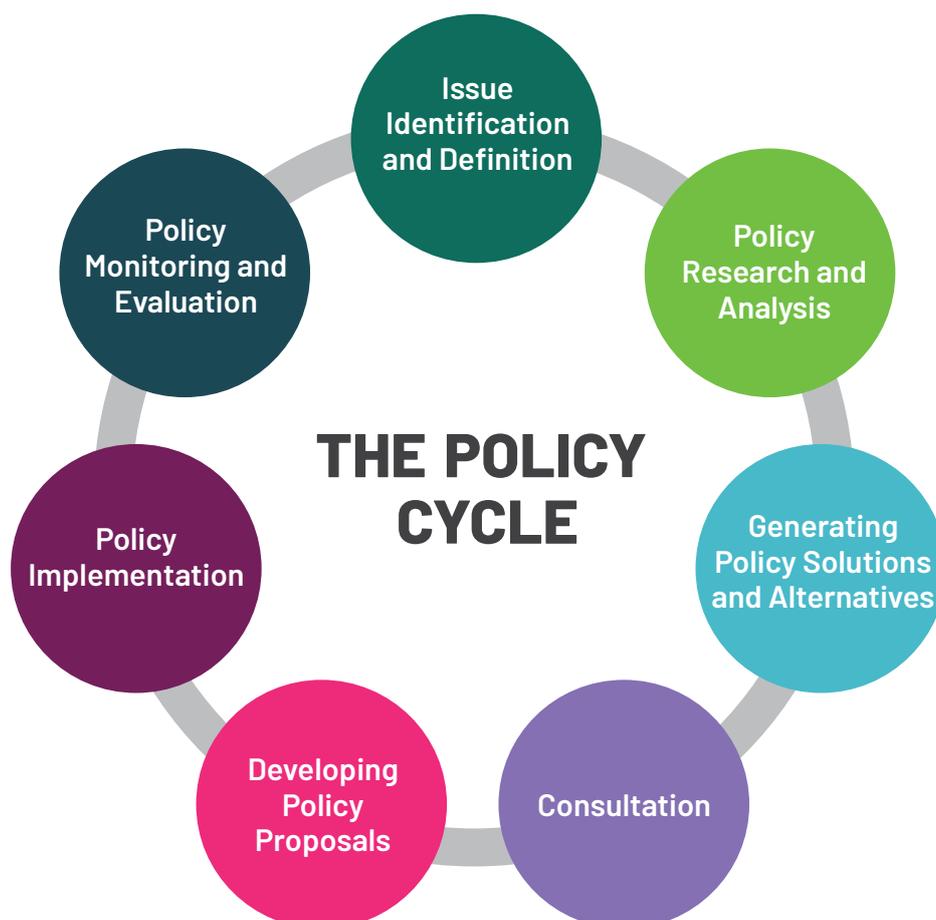


Figure 1. The policy life cycle¹¹

11 Adapted from 'The Policy Cycle'. Policy Newfoundland Labrador. <https://www.policynl.ca/policydevelopment/policycycle.html#consultation>

While evidence should be central to policy development processes, be mindful that many other factors will also play a role; including the experience, expertise and values of the policy developers, the resources available, practical issues, the priorities of other stakeholders and the influence of pressure groups/lobbyists.

There are many opportunities to influence policy, for example, by contributing to a policy review or influencing its terms of reference. A long-term approach is beneficial and your work in advocating for change will ideally remain consistent throughout the policy development life cycle.

Stakeholders in policy making

There are many stakeholders to consider in your advocacy approach. It is vital to establish an open line of communication with civil servants and other relevant personnel involved in setting policy and ideally this should be done before approaching senior politicians. Such posts are not always public-facing and so some detective work and persistence might be required to identify the people you need to talk to.¹² Building cross-party relationships with politicians and their advisors is also useful. Amongst the public affairs stakeholders with whom you may be engaging are the following:

- Civil and public servants
- Professional bodies
- Statutory bodies
- Other charities and non-profits
- Think tanks
- National politicians and Members of the European Parliament
- Government Ministers
- Political advisers
- Cross-party committees¹³

¹² In the Irish context the 'Who Does What' website can be a useful starting point.
<https://whodoeswhat.gov.ie/>

¹³ In the Irish context, for example, the Oireachtas Health Committee:
<https://www.oireachtas.ie/en/committees/32/committee-on-health/>

Which of these stakeholders you engage with will depend on many factors, including whether you have (or want to develop) a political champion, whether you have constituency connections with relevant politicians, how your issue relates to wider policy etc. There are a variety of ways in which you might engage with and hope to influence these stakeholders through your evidence-informed advocacy. These include through meetings, presentations, position and briefing papers, input to a party manifesto or Programme for Government, pre-budget submissions etc.

Using the evidence to influence policy

Whilst global evidence is frequently a starting point, local evidence is critical to inform all stages of the policy cycle. A patient-focused organisation's research can be a significant driver in capturing non-clinical outcomes of the local community and can be hugely valuable to policy makers. You are in a unique position and should make use of all evidence available to you to define the problem and propose solutions, approaching the issues from both a person-centred and societal impact perspective.

In order to do this effectively, complement quantitative data with qualitative evidence and utilise both hard evidence (from scientific research) and soft evidence (for example, the views of an authority figure such as a medical consultant) – both have value, but may be more suitable for different audiences. For example, a party health spokesperson may be very interested in speaking to someone affected by the specific policy issue, whereas policy makers and health service providers may want to see an evidence-based report.

Presenting the evidence appropriately

The way in which the evidence is presented is critical. Policy-makers are overloaded with information from many sources and so presenting your evidence in an accessible and concise way can make their job easier and makes your case stand out. For example, data visualisation tools, such as infographics, are very helpful as they enable you to present a large amount of impactful information quickly and succinctly. Executive summaries also help to make long documents more digestible. Policy-makers need to know more than just the solution, they need to know specific details – the how, why, who and when. It can be valuable to present some alternatives

and a critique of the same, to show that you have considered several options. Whenever possible, include scenarios and data on the cost of doing nothing, along with how taking no action will impact government, national services, society in general and the individuals you represent.

In general, politicians, who are perhaps even more overloaded with requests and information, do not require the same depth of data as policy makers. They are particularly interested in a high-level overview of the issue, along with how many people are affected, where those people are and how you believe they can help. They are also interested in personal stories, in order to help them better understand the issue, and will particularly connect with them if they are from people in their constituency.



Hosting a launch event

Organising an event to launch your evidence-based campaign can be an effective way to target both policy makers and the media at the same time. For instance, invite public officials and politicians to the launch of a report / position paper/ budget submission and also issue a press release and invite media to cover the event. Ensure that the timing of your event works with the weekly schedule for politicians and host the event as close as possible to where they sit.¹⁴ As they might not stay long, aim to repeat key information over the course of the event, provide a brief overview document for them to take away and offer the opportunity for photographs with members of your community.

¹⁴ In the Irish context, such an event could be in the form of a presentation in the AV Room of Leinster House or in a location close to Government buildings. Ideally members of the community you represent will be present to share their stories. The daily Dáil schedule is provided here: <https://www.oireachtas.ie/en/dail-schedule/>

Media as an advocacy tool

As outlined earlier, sometimes your objective will be to secure support for your agenda by working behind the scenes with relevant stakeholders before (if ever) going public with your story. You may be fortunate to achieve your goals using this approach alone. However, the media can be a powerful ally in raising awareness about an issue and drawing attention to the impact a policy or service is having on the people you represent. A PR campaign can help to place pressure on policy-makers and harness public support for your cause.

If you are hoping for media coverage, it is worthwhile considering from the start how your findings might be reported, which can inform how questions are structured. For example, a rating scale that uses specific phrases (like totally disagree, disagree, etc.) is easier for the media to report on than a numerically based scale. It may also be the case that there is on-going media interest in a particular aspect of your issue, which may prompt inclusion of a question about that angle. Budget permitting, it may be beneficial to involve a public relations (PR) expert at the outset, to advise on these aspects and on the timing of a launch for your evidence-based campaign.

Types of media to target

The media landscape is continually evolving, with a growing number of digital and online options to complement traditional print and broadcast media. These options include the following:

- Newspapers may produce **dedicated health supplements**, which will have its own editor and team of staff and/or freelance writers.¹⁵ Similarly, broadcast outlets may have a dedicated health or science programmes or sections on their website.
- If you are seeking **news coverage** of your issue, the news desk of appropriate media outlets is the obvious go-to location. Depending on the news organisation, they may have a specialist correspondent whose role is to cover health or science stories. If not, then you will likely be engaging with a news editor or news journalist on the desk.
- **Current affairs programmes** constitute a significant opportunity on radio and television to secure coverage. Features coverage can provide an alternative way of approaching the issue. In these instances, there can be less of an emphasis on the news angle and a greater opportunity for providing context or alternative perspectives.
- Other avenues to consider are **dedicated health, medical or science websites**.¹⁶
- **Local media** are a major feature of the landscape and should not be overlooked. Most of the regional radio stations feature at least one talk or current affairs programme on their weekday schedules. This represents an opportunity to obtain coverage, although your story may have to be tweaked to reflect a local angle in order to have a better chance of securing coverage. The same applies to regional newspapers.
- **Social media** offers many opportunities to spread your message and to connect directly with key stakeholders. Infographics are particularly impactful in this context.

¹⁵ For example, in the Irish context, The Irish Times Health Supplement.

¹⁶ For example, in the Irish context, irishhealth.com, The Irish Medical Times and The Medical Independent.

Making your issue newsworthy

Just because your issue is important does not mean that the media will have an interest in publishing or reporting on it. The sorts of things the media will consider in deciding whether your story is news worthy are:

- How many people are affected by the issue?
- Who is affected?
- Is there a particular population that is disproportionately affected, for example, children?
- How long has this situation been developing?
- Is there a serious threat to life?

Depending on the answers to these questions and the credibility of your evidence, certain journalists, media outlets or editors might be more interested in your story than others. For instance, features pages often have a strong female readership, so stories about women's health might be viewed favourably by editors.

Taking the tips below into consideration is likely to lead to a more positive engagement with members of the media, both in terms of securing coverage and the quality of that coverage.

- Evidence in the form of **facts and figures** is valued by the media. Be prepared, however, for your numbers to sometimes be reversed. For example, your story that 75% of people who wouldn't do something could be presented as one-quarter who would.
- Think about how you **frame the evidence** within your story. For media purposes, one in five sounds more impactful than 20%.
- Including an element of **controversy** in your story is likely to attract more media interest as it generates not only increased sales, listeners or viewers, but crucially, greater engagement on social media which is appealing to journalists. Tread carefully in taking this approach however; it needs to be balanced with the necessity to retain your organisation's credibility and to preserve your relationships with policy makers.

- Think beyond the information aspect of your story to how it can be **presented visually**. This might mean that your data will be produced as an infographic (which will frequently be generated by the news organisation) or it can extend to photo opportunities to accompany the story. This is especially important in terms of social media pick-ups of the story.
- Media outlets with a reputation for credible news will want to see that the evidence your story is based on is strong and could potentially ask to see the **raw data** to check its validity or to present it in a different way.
- If the issue or campaign is a multi-stakeholder one, make sure everyone is **clear on who takes the lead** in the media coverage. One stakeholder might be able to raise issues that another can't. This might be the case, for example, where there is a patient group and a clinician advocating for the same thing.



Using personal stories to bring attention to your cause

While the focus of this guide is on using evidence to strengthen your advocacy, it is important to bear in mind that individual stories are key to a successful PR and advocacy campaign. There is an increasing movement towards 'no data without stories'. Journalists and other stakeholders in your advocacy campaigns want personal stories and they are an effective way to highlight the human impact of the issue at hand. They put a face on the numbers and make your campaign far more compelling and memorable.

Take a very ethical approach, particularly when dealing with vulnerable people, and make sure the person giving the testimonial is comfortable with their story being highlighted by the media. The experience can sometimes leave people feeling exposed and, having shared their story with a journalist, they most likely won't get to approve it before it goes to print. Indicate to a journalist if some questions are off-limits before the interview takes place. Equally, many people find the opportunity to tell their story a very positive and validating experience.

Conclusion

As patient-focused organisations, we often have the opportunity to use our voice to help bring about improvements for the people we represent. It is our responsibility to be guided by, and use all the evidence available to us, in order to effectively and meaningfully achieve our goals. Whatever approach you take to gathering and generating evidence, perseverance will be key. Be clear about your objectives, aim high and be prepared to spend a lifetime learning about generating and using evidence.

Appendix 1

Additional resources on evidence-based advocacy campaigns

In an effort to keep our guide accessible and digestible, we have kept it brief. The use of evidence to bring about change is an incredibly complex and nuanced pursuit however. For each of the topics we cover here, there is additional information and guidance available. See here for some resources we found particularly useful.

1. Evidence for Good. Alliance for Useful Evidence, 2018.
<https://www.alliance4usefulevidence.org/publication/evidence-for-good/>
2. Using Research Evidence: A Practice Guide. Alliance for Useful Evidence, 2016.
<https://www.alliance4usefulevidence.org/publication/using-research-evidence-a-practice-guide-january-2016/>
3. Communicating research for evidence-based policymaking: A practical guide for researchers in socio-economic sciences and humanities. EU publications, 2010.
<https://publications.europa.eu/en/publication-detail/-/publication/579cb7ba-821f-4967-b3a2-d87556a0bcfe>
4. Building an Evidence Base for your Campaign. The National Council for Voluntary Organisations, England, 2017.
<https://knowhow.ncvo.org.uk/campaigns/campaigning-and-influencing/analysing-the-campaign-issue-and-building-evidence/building-an-evidence-base-for-your-campaign#>
5. The Education we Want: An Advocacy Toolkit. Plan International, A World at School and the Youth Advocacy Group of the Global Education First Initiative, 2014.
<https://www.gcedclearinghouse.org/sites/default/files/resources/180124eng.pdf>

Appendix 2

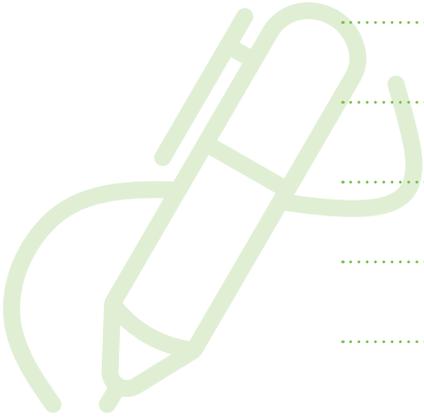
Useful sources of evidence for Irish organisations

- Central Statistics Office:
<https://www.cso.ie/en/index.html>
- Dáil Éireann parliamentary questions:
<https://www.oireachtas.ie/en/debates/questions/>
- Searchable archive of Dáil and written parliamentary questions, the Seanad and all Committee meetings.
<https://www.kildarestreet.com/>
- Department of Health Key Trends:
<https://health.gov.ie/?s=key+trends+>
- European Union Statistics on Income and Living Conditions: <https://ec.europa.eu/eurostat/web/microdata/european-union-statistics-on-income-and-living-conditions>
- Growing up in Ireland: <https://www.growingup.ie/>
- Healthy Ireland Survey (Department of Health):
<https://www.gov.ie/en/campaigns/healthy-ireland/?referrer=/accessibility/healthy-ireland-survey/>
- HIPE (Healthcare Pricing Office): <http://www.hpo.ie/>
- HSE Planning and Business Information:
<https://www.hse.ie/eng/about/who/corpoperf/>
- HSE Social Care Division:
<https://www.hse.ie/eng/about/who/socialcare/>
- Irish Social Science Data Archive:
<https://www.ucd.ie/issda/>
- National Cancer Registry of Ireland: <https://www.ncri.ie/>

- National Patient Experience Survey:
<https://www.patientexperience.ie/>
- National Treatment Purchase Fund:
<https://www.ntpf.ie/home/home.htm>
- Primary Care Reimbursement Scheme (PCRS):
<https://www.hse.ie/eng/staff/pcrs/about-pcrs/>
- The Economic and Social Research Institute:
<https://www.esri.ie/>
- The Irish Longitudinal Study on Ageing (TILDA):
<https://tilda.tcd.ie/>



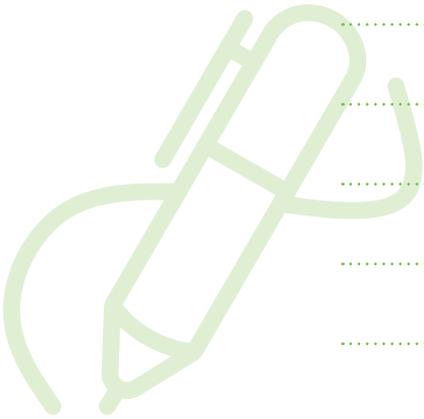
YOUR NOTES



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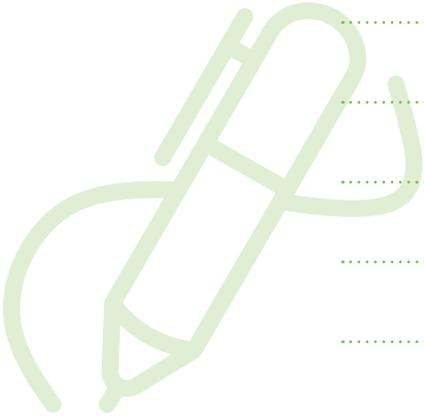
YOUR NOTES



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YOUR NOTES



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