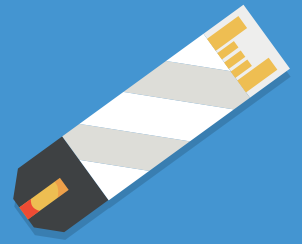


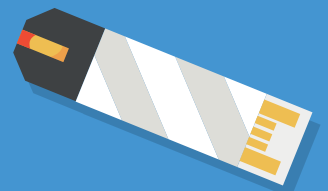


TII INTERNATIONAL



Diabetes Access ADVOCACY TOOLKIT

*Life with diabetes is complicated.
Access to vital insulin, diabetes supplies
and medical care should not be.*



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T1International's Vision

We believe in a world where everyone with type 1 diabetes – no matter where they live – has everything they need to survive and achieve their dreams.

T1International's Mission

We work towards access to insulin, diabetes supplies, medical care and education for all people living with type 1 diabetes. We do this by raising awareness, campaigning and collaborating with existing initiatives, and supporting individuals and organizations on the ground that are working to make life better for people with type 1 diabetes.

Who is this toolkit for?

This toolkit is meant to be used by anyone with diabetes, with a connection to diabetes, or a desire to make positive change in the lives of people with diabetes. It can be used by patients, healthcare providers, and every-day people around the world. It is your starting point for diabetes advocacy and campaigning.

We hope this toolkit will be useful in helping you think through how to make change for people with diabetes in your community or your country. The sections outlined in this document will take you through the steps of understanding the issue you want to tackle and setting goals, developing a strategy and action plan, taking action, celebrating success as well as analysing and evaluating your action. It also offers resources and access to further information to support you with your advocacy.



“ It is health that is real wealth and not pieces of gold and silver. ”

Mahatma Gandhi

1. Understand The Issue



1.1 Context

1.1.1 Setting the Scene

A recent WHO report¹ said that, as of 2014, an estimated 422 million adults were living with diabetes around the world. The same report notes that separate global estimates of diabetes prevalence for type 1 and type 2 do not exist. This lack of data for type 1 diabetes is a big issue because it means our understanding of the scale and depth of the problems faced by people living with diabetes is limited.

If we apply the type 1 prevalence rate of diabetes in the UK, where approximately 10% of people with diabetes have type 1 diabetes, to the whole world we can estimate that more than 40 million people around the globe live with type 1 diabetes today.

The International Diabetes Federation estimates that there are 542,000 children living with type 1 diabetes globally². This number is much lower than the millions of children we would expect to be living with diabetes. This could be because many children with type 1 diabetes are dying before they are diagnosed or before they reach adulthood.

“Most activism is brought about
by us ordinary people.”

Patricia Hill Collins

A large proportion of people with diabetes live in places with inadequate healthcare, so there are likely millions of people with both type 1 and type 2 diabetes at risk of death due to lack of insulin, diabetes supplies, healthcare, or diabetes education.

Even if they survive, people around the world living with type 1 diabetes face many obstacles such as an inability to keep insulin cool, a lack of ketone strips, glucagon injections, and other diabetes supplies, as well as a lack of support and education.

So, there is probably one (or many) things about diabetes in your community or country that you want to change.

Key Facts & Statistics:

- 50% of people around the world in need of insulin cannot reliably access it because it is unavailable, unaffordable, or bothⁱⁱⁱ
- Monthly out-of-pocket costs for diabetes supplies the USA are anywhere from \$0 to \$1700 USD^{iv}
- In Syria, up to 77% of income can be spent on diabetes supplies, if any are available^v
- Monthly costs for diabetes supplies in Brazil can be as much as \$700 USD, or 82% of a person's income^v
- Full diabetes management in Kenya could cost about \$120 USD per month, but the average monthly salary in Kenya is \$216 USD^v
- Discontinuation of insulin use was the leading cause of diabetic ketoacidosis in 68% of people in a USA inner city^v

These issues affect us all, whether we live with diabetes, know someone with diabetes, or care about human rights.

The great news is you can do something about these injustices. Anyone can be an advocate, so even if you have never done this before, you can start with small actions and gain experience along the way.



1.1.2 What is Advocacy?

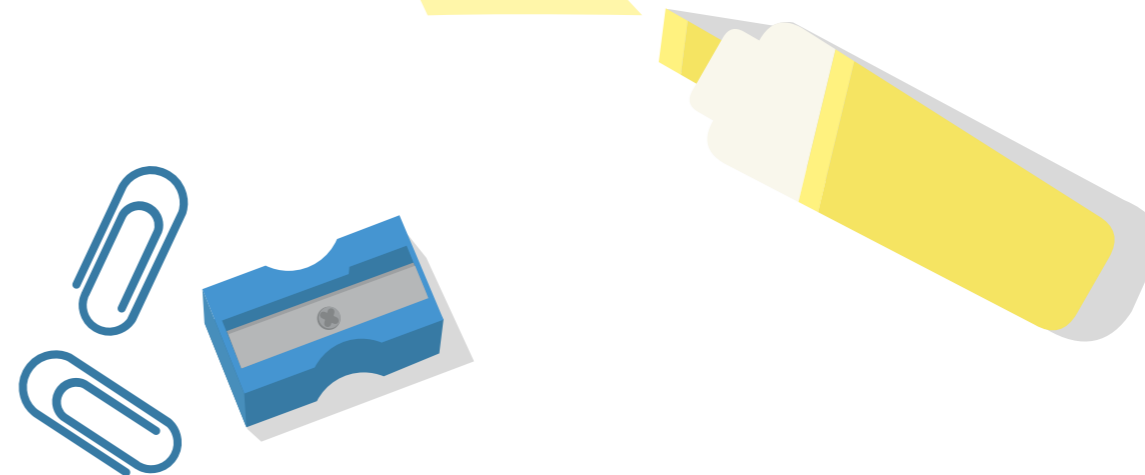
A short, general definition of advocacy is given in the Oxford English Dictionary as:

“Public support for or recommendation of a particular cause or policy.”

Advocacy is often used as an umbrella term for a range of actions like speaking out to raise awareness, meeting with or writing to politicians about an issue or cause, or lobbying (which we will talk about later) with other people and organizations to make a difference.

This is still a bit unclear, isn't it? Advocacy can mean different things to different people, but don't be intimidated by the idea.

At T1International we believe that advocacy means taking action to achieve specific changes in policy or practice that benefit people with type 1 diabetes.



Are advocacy and activism the same thing?

Advocacy is closely linked with **activism**. Activism is defined as: *The policy or action of using vigorous campaigning to bring about political or social change.*

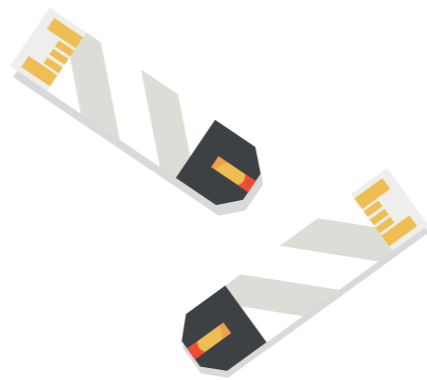
In other words, an **advocate** sits at the table and creates dialogue with policy makers and others to influence change, while an activist is out there protesting, rallying, or taking more physical action to push for change.

Activism can be an activity that is part of advocacy and both are important parts of any plan to create social or political change.

Good and effective advocacy is usually carried out strategically within a certain time frame.

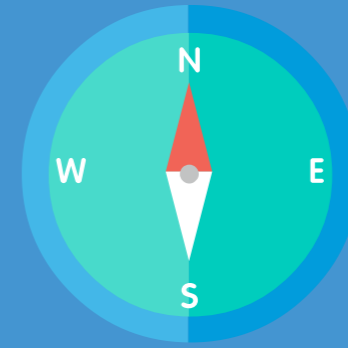
Remember that you do not need to have a lot of money or resources to carry out successful advocacy. You just need lots of passion and commitment!

Now, let's get started with the advocacy process.



“Never be afraid to raise your voice for honesty and truth and compassion against injustice and lying and greed. If people all over the world would do this, it would change the earth.”

William Faulkner



1.2 Defining Your Goal

1.2.1 Your Issue

It is time to ask yourself, 'what is the issue I am trying to solve?' People in your community probably face many issues related to their diabetes. Maybe insulin prices are too high, maybe there is no access to test strips, or maybe there is a lack of diabetes education, or a certain technology is too expensive.

For your advocacy to be successful, it is important to pick one issue to focus on. For some, this will be an easy choice. For others, it will be tricky. Remember, this is only your first issue and first action plan. Once you succeed, you can tackle the next issue, and the next, and the next...

Be specific about the problem you want to address.

Here are some examples:

- Insulin is not always available in rural pharmacies for people who need it
- The cost of syringes to inject insulin is not affordable for people with diabetes
- Test strips are too costly so people can only test their blood sugar when they go to a clinic
- Psychological support is too expensive for a person with diabetes to access
- Emergency departments in hospitals do not properly care for people with type 1 diabetes

For the purpose of this toolkit, we will use the following example to illustrate the advocacy process:

A local clinic can no longer provide free insulin to its patients and the cost is not affordable for most of the patients to pay out of pocket.



1.2.2 Your Goal

You have identified your issue and now it is time to decide exactly what you want to change about that issue. This will be your goal.

A simple tool to use when trying to narrow down your goal is called the **5 Whys**. This is used to explore the cause-and-effect relationships underlying a certain issue. The **5 Whys** will help you to determine the root cause of an issue by repeating the question “Why?” five times, or as many times as needed.

There can be more than one cause for an issue, so you might have to do the **5 Whys** more than once – one time for each cause. Sometimes you might not know the answers to every ‘why’ question, but the process helps to narrow things down. It will help you understand what further information you need before you can set your goal and plan your actions.

Here’s an example:

1. Why can’t the clinic provide free insulin anymore? Because there is no longer money for it in the budget.
2. Why is there no longer money for it in the budget? Because the government cut the funding at the clinic.
3. Why did the government cut the funding at the clinic? Because the government does not understand the consequences of their cuts.
4. Why doesn’t the government understand the consequences of their cuts? Because there is a lack of understanding of the longer-term costs of diabetes to the government.
5. Why is there a lack of understanding of diabetes costs? Because officials do not always take into account that spending in the short-term could save expensive hospital admissions and complication treatment costs in the future.

This has helped us arrive at a potential specific goal:

To get the government to reinstate the budget for insulin at the clinic by showing them that it will cost more in the long-run if they do not fund insulin.

1.2.3 Objectives

Now it is time to set your objectives. These are the important landmarks or steps that you will take to reach your goal. Try to be realistic, but do not be afraid to aim high. For example, one of your objectives may not be achieved, but you might have started a dialogue with the government about these issues which can lead to success in the long-term.

The objectives need to be SMART:

- **Specific** – Have you targeted a specific area for improvement?
- **Measurable** – How will you know you have succeeded?
- **Achievable** – How can the goal be accomplished? How realistic is the goal?
- **Relevant** – Does this seem worthwhile? Is this the right time? Does this match our other efforts/needs?
- **Time-bound** – When will the result be achieved? (your action may have a scope of anywhere from weeks to years)



Our objectives for the goal to ensure that the budget is reinstated for insulin might be:

1. In the next three months, obtain data about the long term costs of not providing adequate funding for insulin and get buy-in from the clinic to work with your team to achieve this goal.
2. In the next six months, set meetings with at least three government officials who can influence the health budget.
3. In the next six months, hold at least four meetings with patients and patient groups to help us carry out our action plan.
4. In the next eight months, secure five pieces of press coverage related to our goal, pressuring governments with stories from those most affected.

Each of your objectives will have more specific actions underneath, but this is the start of your action plan.



1.3 Audience & Messaging

1.3.1 Target Audience

Think about who you want to influence and how.

In advocacy work, there are usually two main audiences: decision-makers and influencers.

1. **Decision-makers** (your primary audience): Which individuals or groups make the decisions you want to influence?

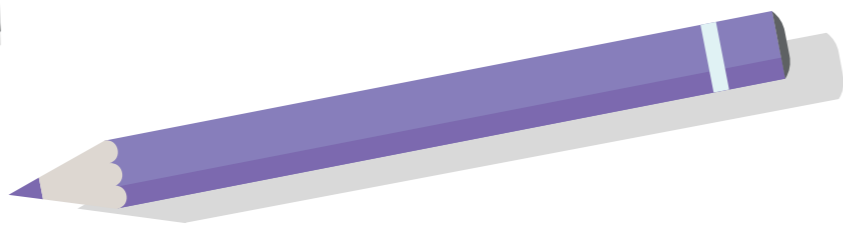
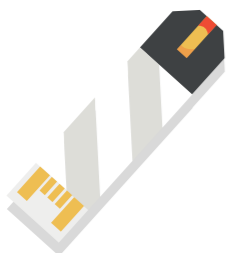
In our example: Elected politicians, business leaders, government workers

2. **Influencers** (your secondary audience): Who has the most influence on the decision-makers?

In our example: The media, health professionals, celebrities, patients and fellow advocates

You will want to start thinking about how you can influence the decision makers, but also the influencers. How can you get them on side?

Remember: different people have different levels of awareness. Some will be ready to work actively on the issue you are presenting, while others will require more information about the issues before getting on board. Preparing your key messages is essential for raising awareness.



1.3.2 Key Messages

Your key message is the most important element that your audience will use to decide if they support you and your cause. It should be:

- Compelling, convincing, clear and concise – ideally you should be able to communicate it in less than one minute
- Consistent – if your message is reinforced by a combination of sources people are more likely to believe it

Some of the talking points under point 1.1.1 at the beginning of this section might support your key message, or you might want to tailor your message to your country and cause, depending on your goal and objectives.

Here's an example of a general key message:

In [insert town] people with type 1 diabetes are dying an early death and suffering from costly complications because they can no longer access free insulin supplies from their clinic due to budget cuts. In [insert country] the cost of insulin is unaffordable for many people living with type 1 diabetes because it can cost as much as [insert number]% of someone's monthly salary.

We need the government to reconsider because these cuts in funding will lead to many diabetic complications. This will cost the [insert country] healthcare system more money in the long run by increasing complications and hospital admissions for people with type 1 diabetes. We implore the government to re-instate the budget for insulin to save lives and save costs to the government in the long run.

You may need to edit your key messages as your advocacy goes through various stages. Once you have raised awareness of the issue, for example, you will likely want to have more targeted, action-oriented messaging.

Now you have set your goal and objectives, considered your audience, and have some key messages. It's time to create your advocacy action plan!

ⁱ <http://www.who.int/diabetes/global-report/en/>

ⁱⁱ <http://diabetesatlas.org/key-messages/7.html>

ⁱⁱⁱ <http://haiweb.org/wp-content/uploads/2015/11/ACCISS-Fact-Sheet-1-Inequalities-in-Insulin-Market.pdf>

^{iv} <https://www.t1international.com/insulin-and-supply-survey/>

^v <http://www.ncbi.nlm.nih.gov/pubmed/21775761>



Case Study: Emergency Insulin Prescription Refills

Dan, parent of a child with type 1 diabetes in the USA

Issue: All states in the USA have an emergency prescription refill law. This law is in need of updating because it is not enough to save the lives of people with type 1 diabetes. Insulin and several other drugs do not come packaged in a way that allows for a 3 day emergency refill by the pharmacist. Many pharmacies do not allow for an insulin package to be broken open for smaller distribution and if they do, they might be breaking the law. If a package is broken open, either the patient pays out of pocket, or the pharmacy must pay for the charges if the insurance company refuses the claim.

In January of 2014, this issue claimed our son Kevin's life. Many people with type 1 diabetes have suffered, walking away from their pharmacy with no insulin until they contact their doctors because the law prohibits emergency refills in certain situations.

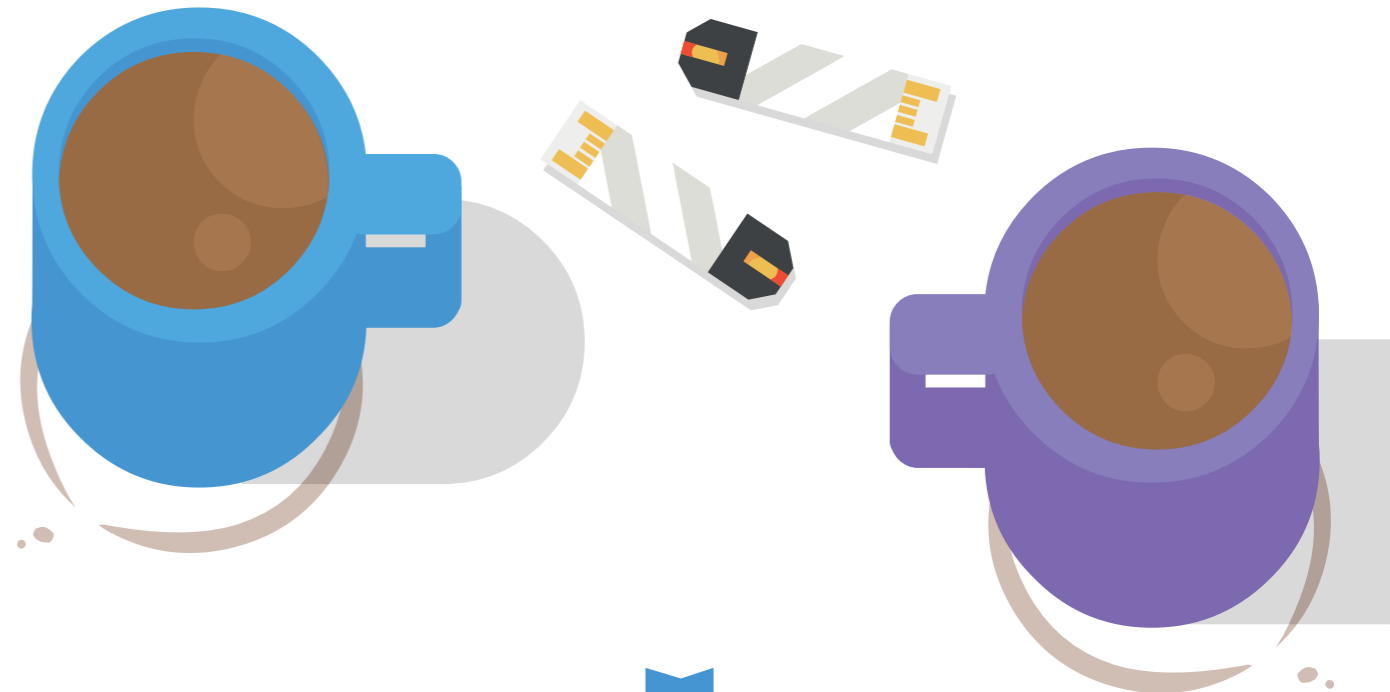
Actions: We contacted our State of Ohio Senator with Kevin's story and the need to change this law. We spoke with our Senator for over an hour face to face with a personal story and plea. She understood the importance of this and immediately went to work. She engaged the help of a fellow Senator who is a pharmacist and owns his own pharmacy, and she got the help of other Senators and House Representatives.

We have succeeded in gaining TV news coverage on the local, state, and national level and much media coverage over the past two years. We made two trips to our state capitol and gave testimony before the committees. This proved to be very important because the committees often hear factual or technical testimonies, but you could tell our personal story touched the entire committee and audience. We also had full support of the pharmacists association and they helped draft the wording of the legislation.

As the bill progressed, even though there was no opposition, we reached out to the Majority Leaders in the House and Senate and met them personally. I stayed in constant contact with my Senator and house representative. I also got to know their aides. There is a balance to strike to make sure you give them room to do their work while pushing them and staying involved.

Outcome: This led to a change to the law that allows pharmacists to help people that need insulin immediately until they can contact their doctor or get a new prescription. It is a simple law change and was passed 100% bipartisan at all voting levels. The law was signed by Ohio Governor Kasich in 2015. This law affects anyone on any life sustaining medications that are unable to be dispensed in a three day quantity.

It took fourteen months from the time we contacted our Senator until the governor signed the bill. That is very fast for a bill to become law in the USA. We want to ensure that there is a law in every state in the USA regarding emergency refill of prescriptions that have expired or have no refills available. Slowly all states are getting on board to make this change. Through our advocacy efforts engaging the public as well as lawmakers in all states we have passed this law in several other states since it was signed in Ohio. The State of Ohio even put Kevin's law on the law portion of the pharmacy exam, so pharmacists are learning in school that patients come first.



2. Plan Your Action



2.1 Research & Analysis

2.1.1 Understand Political & Social Contexts

You have defined your objectives, considered your target audience and created key messages. Now it is time to take a step back and understand the context of your issue so that you can plan your next steps.

Key questions to think about:

- Are there any potential political barriers to achieving your objectives?
In our example: potential corruption, bad policies, resources directed towards alternative government priorities
- Are there any practical or procedural barriers in the way of achieving your objectives? **In our example:** limited funding, transport restrictions, lack of time
- Historically what has been done by others trying to achieve these objectives or similar objectives? Is there another group of people that were successful in changing government's mind related to health budgets?
In our example: another clinic facing similar problems managed to solve theirs, HIV/AIDS activists secured more government funding
- What can you learn from the efforts of others?

You want to avoid reinventing the wheel. Learn as much as possible about what has already been done and what has succeeded or failed in the past. This will make it more likely for you to achieve your objectives.

Through internet searches, contacting like-minded advocates, organizations and government officials, you can also build a picture of why certain issues remain unresolved and what more is needed to address them.

2.1.2 Stakeholder Management

When preparing your advocacy plan, you will also need to spend time analysing the relationships of all stakeholders involved.

Key questions:

- Who are the primary people directly impacted by your objectives?
For example: government/policy makers, clinic staff, and patients
- Who within this group of primary people can be identified as a leader?
For example: the head of the diabetes team at the clinic, government officials, or a strong patient advocate
- Who could be influential partners and what types of support could they provide?
For example: a key contact in the media could help get wide press coverage and push for a government response

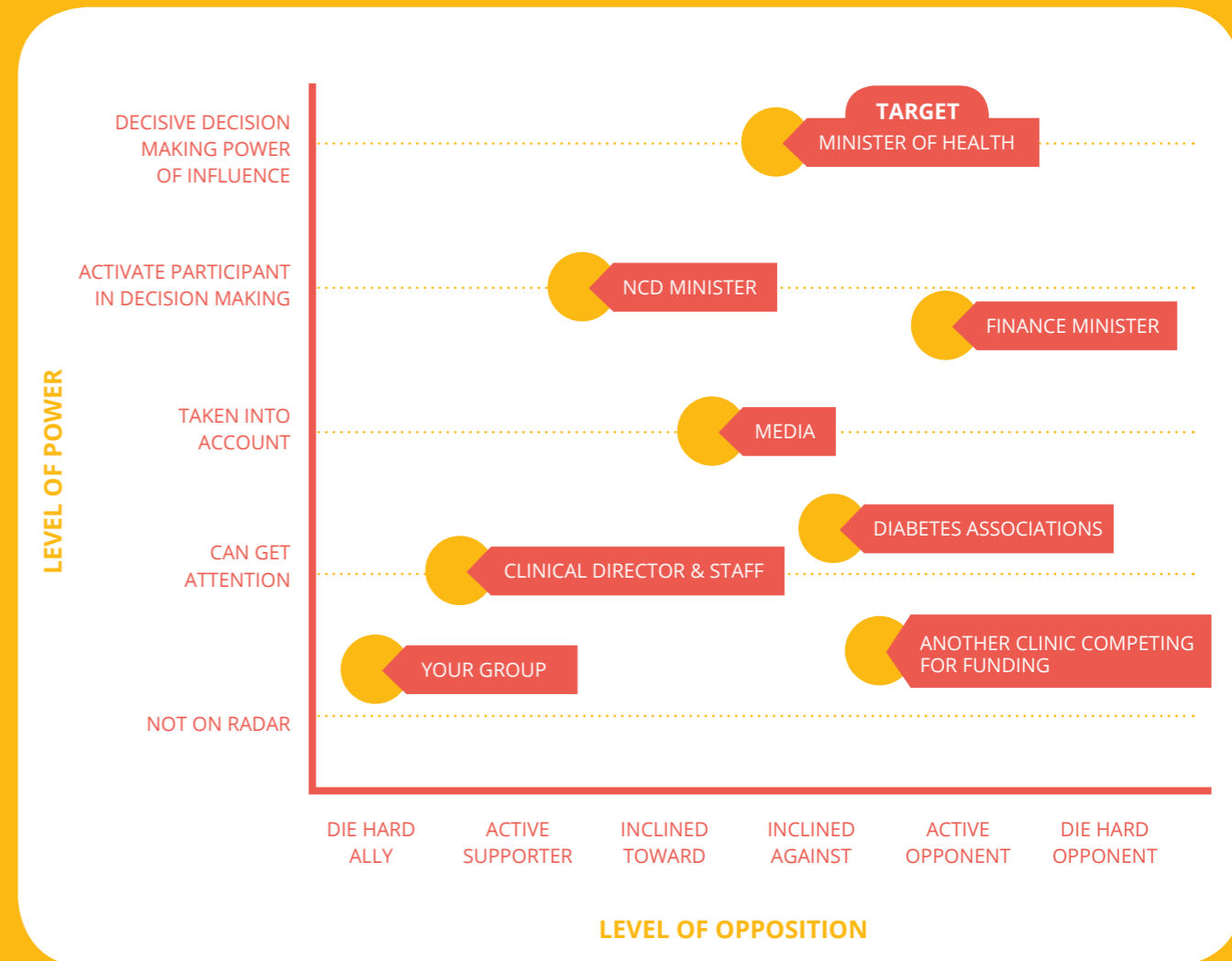
It can be useful to produce a **Power Map** detailing your findings when answering the questions above. By seeing all the influential stakeholders on one page you may be able to find ways they can engage with each other to maximize potential pressure and influence the key decision-makers for each objective. The graphic on the right is based on a map from Advocates for Youth.¹

Remember, there are different levels of engagement with all advocacy: leaders, members, and supporters.

Members are people that have committed to taking action and are part of your team. Supporters are vocally supportive of your advocacy, but have not taken action yet. You always want to be adding new supporters to your team while building the level of understanding and commitment from members. It helps to identify members in your team of advocates that could be good leaders and to spend a little time working with them to build their confidence and your confidence in their understanding of the goal.

Leaders can bring in new supporters and will be important parts of your team, reminding you that you are not alone in your goal!

POWER MAP



Source: *Advocates for Youth*

“How wonderful it is that nobody need wait a single moment before starting to improve the world.”
Anne Frank

2.1.3 Reinforce your Aims with Evidence

Feeling deeply passionate about a cause is empowering and important for advocacy. It is also important to deliver your key messages in ways that will achieve the biggest impact. This can feel overwhelming, but researching to find evidence for your messages will help you to feel more confident.

Collate and record facts and figures, and speak to people about their experiences to build strong and reasoned arguments. Quotes from trustworthy people such as academics and decision makers will also boost your authority.

Here's an example statement, backed by evidence:

Providing insulin at [name of clinic] will be cheaper in the long run by an estimated [insert amount]. According to the clinic, [insert number] fewer patient admissions to the hospital for complications will occur each year. With each patient costing upwards of [insert amount], the cost of insulin is small in comparison.

You can create similar statements using WHO dataⁱⁱ, or data from your country's health agency.



Data Sources

The International Diabetes Federation holds the most regularly updated data in their Diabetes Atlas, so we suggest starting there when looking for diabetes prevalence data. However, data for many countries is still lacking. Therefore, more and better data collection might be an area where you might actually want to advocate.

T1International also prioritizes data collection in underserved areas and is pushing for more diabetes registries and research. We will support you however we can to find the best data for your advocacy goals.

In addition to online research, you can reach out to your local diabetes association, doctors and professors, and other connections to try to collect any and all available data to support your goal.

2.1.4 Explore Health as a Human Right

Health is a basic human right and can strengthen your advocacy.

Explore how Human Rights have been applied to similar health issues and select key arguments to apply to your goal.

The 1948 UN Declaration of Human Rights states:

*“Everyone has the **right to a standard of living adequate for the health and well-being of himself and of his family**, including food, clothing, housing and **medical care** and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.”*

T1International has created resources about health as a human right for people with diabetes.ⁱⁱⁱ These are available on our website and free for use.

2.1.5 Useful Analysis Tools & Techniques

There are many useful tools available to help you while in the planning stages. You can use one or all of the following to analyze your goal and objectives. These are not outlined in detail here, but more information and examples of these tools can be found in our corresponding Facebook group called **Diabetes Access Advocacy (T1International)**^{iv}.

- **SWOT Analysis** – assess Strengths, Weaknesses, Opportunities and Threats
- **PEST Analysis** – looks at Political, Economic, Social, and Technological barriers and how to overcome them
- **Problem Tree** – uses a diagram to map solutions by breaking out the cause and effect of each issue
- **Force Field Analysis** – identifies the driving forces and restraining forces impacting each of your objectives



2.2 Your Advocacy Skills

After completing detailed research and analysis you will have a more comprehensive idea of what the potential challenges are in achieving your objectives, as well as the possible solutions and who you will target for participation in achieving your objectives. It's almost time to plan your actions.

2.2.1 Build & Use Your Advocacy Skills

Central to your advocacy strategy is utilizing three advocacy skills:

1. The ability to work collaboratively with multiple stakeholders
2. The ability to frame an issue effectively
3. The ability to conduct on-going strategic analysis

Dr. Kibachio Joseph Mwangi, Head of Division of NCDs in Kenyan Ministry of Health, helps explain these skills further. He emphasizes that to get the change you want to see, sometimes you have to make the politician think it was their idea.

He stresses the importance of engaging with politicians because, **"we are at the mercy of them."**

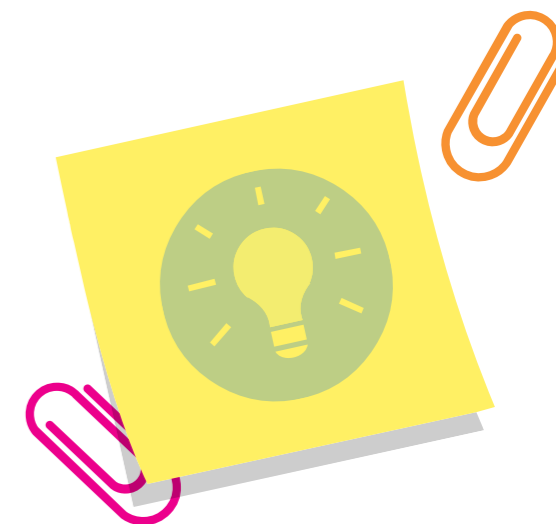
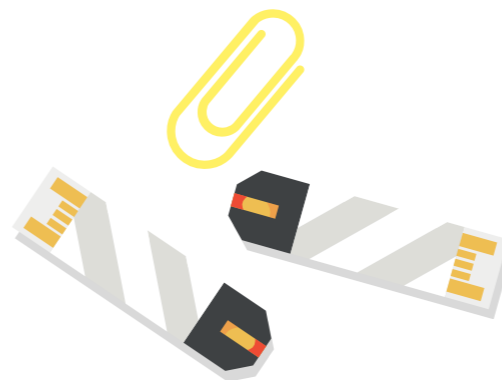


“ I raise up my voice not so I can shout but so that those without a voice can be heard. ”

Malala Yousafzai

These helpful tips from Dr. Kibachio offer valuable insight into the perspective of someone working within the government.

1. **Work on your communication skills** – buy a mirror and practice speaking in front of it!
2. **Be knowledgeable but not condescending, passionate but emotionally balanced** – otherwise the policymaker might get turned off
3. **Time is precious and the policymaker has a very full schedule** – make sure you are prepared and organised (have your key message ready so that you can be clear and engaging about what you want when you find yourself face to face with a policymaker)
4. **Your priority is not theirs** – make sure they understand why your issue should be their priority
5. **Know how the system works** – the policymaker doesn't want to spend time trying to teach you about these things, so do your research to make sure you understand the decision-making process and who you need to talk to
6. **Come with solutions, not just problems**
7. **Be assertive but patient** – you may be very angry or upset, but if you don't appear tempered this will also be a red flag to the policymaker
8. **Be flexible and adaptable** – you might not get what you want the first time, but you have to persist and show that you are willing to bend
9. **Be part of a crowd** – you make more impact in a bigger group that is calling for change because a policymaker will not care too much about one person's problem
10. **Respect the neck, it turns the head** – even if you do not like the policymaker, you must get them to use your ideas in order to accomplish your goals



2.2.2 Prepare for Potential Challenges & Risks

As part of your research you will identify potential challenges and risks. Your Advocacy Plan is your opportunity to document these and prepare for ways to overcome them where possible. This will be an on-going process and you will need to continue documenting and communicating these to the relevant stakeholders. It will also be useful to have this list for any future efforts you undertake.

It is helpful to conduct a risk assessment to explore whether addressing challenges would be worth the cost in proportion to the benefit you may gain. A practical method of managing risks is to give risks a colour code: yellow for low risk, orange for medium risk and red for high risk. Red risks might want to be avoided all together, but orange ones might be worth taking if you discuss the worst possible outcome and how to avoid negative outcomes.

You might also want to group your risks into different risk categories. For example, maybe there are a lot of risks around lack of funding or resources. These can go in a risk category together because they are all related to each other.



2.2.3 Avoid Common Pitfalls

Here are a few tips to avoid common pitfalls in advocacy.

1. Do not make your goal too big or complex

As advocates, we want as much change as possible, as soon as possible. Real and lasting change usually happens step-by-step, rather than all in one big bang. If you set an unachievable goal or do not make it specific enough, you may get disheartened or demotivated. Focus on targeted goals and think about incremental change.

2. Do not have everyone as your target audience

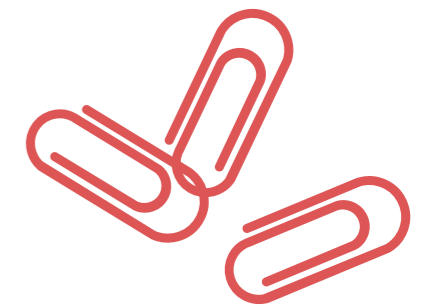
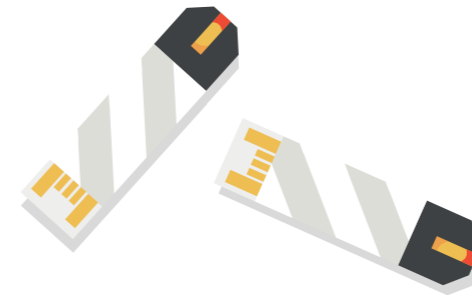
The general public is not your target audience. If you try to reach everyone at the same time and with the same message, you will end up reaching nobody. This is very important for diabetes advocates because we have limited resources for our programmes and campaigns. You need support for advocacy, so make sure you engage an audience who will be on board with what you are trying to achieve.

3. Do not complicate your messages

If you really want to reach that target audience, then your materials – leaflets, websites, press releases, etc. – need to be clear and easily understood. Not everyone is literate, so you might want to include images to illustrate things alongside explanations where possible. Unless your materials are written for scientists or legal experts/law makers, you should aim for a low reading level (usually no higher than 8th grade).

4. Do not overload your audience

In business, if you provide people with too many choices they will buy less than if you gave them fewer options. In advocacy, if you give people too many reasons to take action, they might ignore them all. For instance, there are many reasons why insulin is needed at free or reduced prices in the clinic, but you will be most effective if you match the right motivations to the right audience. Government officials probably won't care about quality of life as a reason for providing insulin, but they will care if it reduces government spending later.



“ There may be times when we are powerless to prevent injustice, but there must never be a time when we fail to protest. ”

Elie Wiesel

2.3 Example Advocacy Plan

Now that you've done the research and the mapping, you're nearly ready to go. This simple strategy plan puts everything together and fits directly with specific objectives.

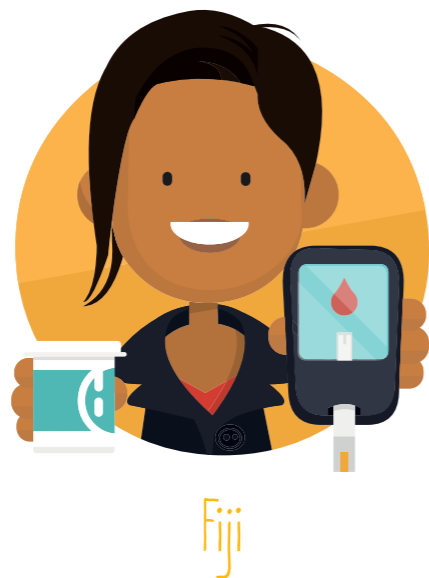
GOAL	OBJECTIVE 1	OBJECTIVE 2	OBJECTIVE 3	OBJECTIVE 4
<i>To get the government to reinstate the budget for insulin at the clinic by showing them that it will cost more in the long-run if they do not fund insulin</i>	In the next three months, obtain data about the long term costs of not providing adequate funding for insulin and get buy-in from the clinic to work with your team to achieve this goal.	In the next six months, set meetings with at least three government officials who can influence the health budget.	In the next six months, hold at least four meetings with patients and patient groups to help us carry out our action plan.	In the next eight months, secure five pieces of press coverage related to our goal, pressuring governments with stories from those most affected.
QUESTIONS TO CONSIDER	1	2	3	4
Who do we need to influence?	<ul style="list-style-type: none"> Academics Clinic Director Diabetes Specialists 	<ul style="list-style-type: none"> Leader of certain political party Regional or local leader (eg. the mayor) 	<ul style="list-style-type: none"> People living with type 1 diabetes Local diabetes Associations Patient groups 	<ul style="list-style-type: none"> Key contacts in the press and media
What message do they need to hear and from who?	<ul style="list-style-type: none"> "We need your support, your financial evidence, your testimony and your expertise." 	<ul style="list-style-type: none"> Testimonials from individuals What the cost savings to government would be in the long run 	<ul style="list-style-type: none"> "We need your stories and your strength in numbers to join the cause." Clear ways they can support our plan to achieve our aims 	<ul style="list-style-type: none"> Simple messages that pull on heartstrings Testimony from individuals Economic benefits such as cost savings for the government
How are we going to influence people and make sure they hear the message?	<ul style="list-style-type: none"> Let them know you want to help Meet and listen to ensure you are on the same page Let them take the lead where necessary Recognize their time limitations 	<ul style="list-style-type: none"> Use connections to set up a meeting Write a letter with patient signatures to meet and discuss the issue Makes phone calls to government representatives Get 5,000 signatures on a petition (online) 	<ul style="list-style-type: none"> Let them know you want to work together Listen to ensure you are on the same page and have heard their views Give them specific actions and show how it will positively impact their lives 	<ul style="list-style-type: none"> People with diabetes reach out to the media directly to share a story Use and find any connections to set a meeting Hold a rally or public event outside government buildings
What do we need to make this happen? (resources, time, peoplepower, etc.)	<ul style="list-style-type: none"> Information, resources and experts in the field to collect the data Access to meeting space to talk with the clinic Leader(s) to represent our group to the clinic team 	<ul style="list-style-type: none"> Funds for travel to meet policy makers Funds for leaflets and other resources to distribute to those with influence Supporters and time to call and write letters 	<ul style="list-style-type: none"> Three strong leaders to manage advocates and recruit new supporters Meeting space to talk with patient groups Funds for leaflets and resources to demonstrate our plan 	<ul style="list-style-type: none"> Several people with diabetes who are willing to approach the media and share their story A large number of supporters who are willing to take part in a public event
What other steps will lead to this change?	Continued open communication and collaboration with the clinic and leaders	Pressure from pharmacies and other influential stakeholders in the country or region	Collaboration with healthcare professionals who see diabetes complications day-to-day	Media coverage in newspapers, radio and online news outlets at all levels (local, national, etc.)
When will we know we have succeeded?	When health professionals at the clinic can confirm that the budget has been reinstated	When the government re-allocates the budget to the clinic	When patients can confirm that they are receiving their insulin	When the media have covered our stories and helped to put our messages in the spotlight

ⁱ <http://www.advocatesforyouth.org/publications/publications-a-z/2229-youth-activists-toolkit>

ⁱⁱ <http://www.who.int/mediacentre/factsheets/fs312/en/>

ⁱⁱⁱ <https://www.t1international.com/resources>

^{iv} <https://www.facebook.com/groups/T1InternationalAdvocacy/>



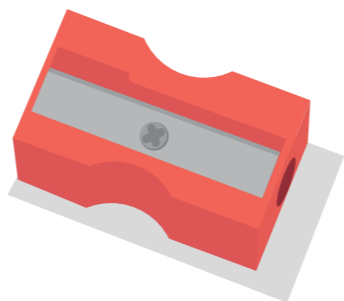
Case Study: Test Strip Customs Duty

Shivanjani, person with type 1 diabetes in Fiji

Issue: In Fiji, there is no mandatory health insurance for the general public. Most people rely on the government hospitals for their medical needs and supplies. All health insurance plans in Fiji cover insulin, but not blood glucose machines and strips.

Less than 20% of the population has health insurance, so most people must pay out of pocket for their test strips. A pack of 50 strips costs around USD \$30. This is extremely expensive for the general public whose average wage is around \$100 USD weekly. Buying strips for type 1 children becomes a secondary matter when people are struggling to put food on the table. Parents are left with two options: either forget about diabetes management or resort to other solutions to try to pay for diabetes supplies.

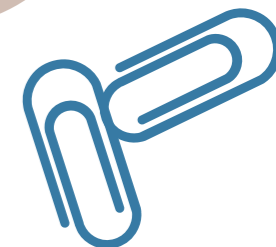
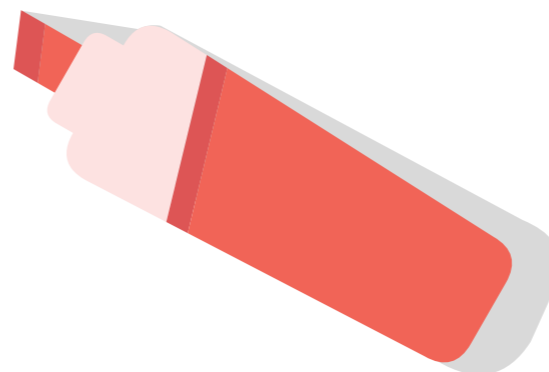
Another issue was that in the past, other countries would sell their soon-to-be obsolete stock of strips to Fiji at cheap prices. Patients would purchase the glucose machine and strips at these cheap prices but their supply of strips would run out a few months later and then the machine was of no use because there were no available strips for it.



Actions: In 2015 the concern about the high prices of blood glucose machines and strips meant that the organization *Young Diabetes Fiji* asked for a subsidy for these things. We provided a lot of information and evidence together with a proposal which was presented to the government.

We also partnered with the Consumer Council to advocate on the above issues. We did research and collected evidence of the need and benefit of access to a continuous supply of appropriate test strips. We went patient to patient, gathering information in-person, because in Fiji less than 50% of people have internet access. We analysed the evidence, wrote petitions to ministers and brought the issue to the media with the help of the consumer council.

Outcome: Along with our advocacy partners we succeeded in getting the government of Fiji to lower the customs duty from 5% to 0% on blood glucose machines and test strips for 2016. Thanks to our efforts the issue is pretty much solved. Not only is the customs duty at zero, but pharmacies now can only offer blood glucose machines that guarantee the supply of strips for the next 5 years. This is a binding agreement between the government and pharmacies.

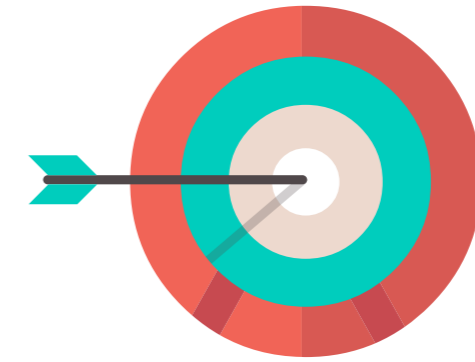


3. Take Action



“Never doubt that a small group of thoughtful, committed, citizens can change the world. Indeed, it is the only thing that ever has.”

Margaret Mead



3.1 Implementing your Advocacy Plan

3.1.1 Understand Advocacy Activities

Advocacy fits into a range of activities that include organizing, lobbying, mobilizing and campaigning.

Organizing is the method of uniting as a group to build power and using the power to create positive change in people’s lives¹. It is a way to ensure that the views represented in advocacy come from those who are actually affected by the issue².

For example, maybe you do not personally have trouble with access to insulin, but you know a portion of the population in your country does face this. Be sure to get as much input from the people affected by the lack of access to insulin as possible. It will be best if you can bring them into your advocacy work and build them up as leaders.

Mobilizing is the practice of building relationships and securing partnerships in support of your goal or activity. One example of mobilizing would be a sports team coach assembling and motivating his team to go into an important game. In advocacy, we want to assemble our people, our data, and our messages to prepare for social change.

It is important to remember that you cannot mobilize people unless you ask them to do something. Once they have been informed about issues, many people want to know what the solutions are. Mobilizing people means asking them to become part of the solution by taking action. This creates commitment and a sense of unity.

Lobbying takes a targeted approach. It happens when people that are leading a campaign reach out to a small, specific group of people. They meet directly with officials to try to change policy. Remember when we looked at influencers in section 1.3 and power structures in section 2.1? You will want to focus most on the influencers you have identified when it comes to lobbying activities. You will also want to refer back to our advocacy skills section and the 10 tips for approaching policy makers.

Campaigning is a larger platform which publicly promotes an agenda. It typically involves a large number of people and speaks to a wide audience who can hear the message of the advocates.

Some ideas for campaigning activities include:

- Ask supporters to write letters en-masse to a certain target (government official, pharmaceutical company, etc.). Letters and emails can be stronger when they are written with a personal perspective rather than a template, but key messages should always be included. Our Type 1 Access Charter includes an example letter and can be found on the websiteⁱⁱⁱ.
- Carry out a public stunt such as a march, protest, or demonstration to get the attention of the public and the media. Do your research to ensure you avoid any unlawful activities, and remember to assess risks beforehand. Hand out leaflets to inform the population about the issues and actions that they can take.

Escalation of Tactics

This idea from Advocates for Youth shows how you can gradually increase the pressure on the people you want to influence^v. It is one strategy for achieving an objective through targeting specific people.



Source: *Advocates for Youth*



3.1.2 Media & Online Advocacy

Seek partnerships with newspapers, radio stations, journalists or documentary filmmakers to get your message out in a big way.

Case Studies

Develop case studies of people living with diabetes that fit with your key messages and narrative. Using an emotional approach is OK as long as the information you are sharing is accurate and the person sharing the information has agreed for it to be shared publicly. Along with the case study you should present a solution to the issue, with practical steps for decision-makers to take.

Engaging the Media

In order to engage the interest of the media, a story needs to have a new or exciting aspect to interest not only the journalist, but the general public. Think of ways you can pitch your cause or tie it into a popular current issue. Another way to grab attention is focusing on an emotional element. You could interview someone local who has suffered due to lack of access to insulin, for example. In other cases it might be better to focus on the high government spending that could be reduced with less diabetes complications. Or maybe you want to tie the issue into the economic situation if it is a journal with a focus on the economy. Look at each media outlet and consider what type of content they are looking for.

“ The future depends on what you do today. ”

Mahatma Gandhi

The Media Beast

Remember that you do not always have control over how the story eventually appears, so be prepared for this. The media might print inaccurate stories or change the information you submit to them. Sometimes publications will amend their work if there are factual inaccuracies, but more often than not they will fail to do this. You can combat this by having as much information about your cause available online as possible and by being ready to answer any press queries with the most accurate information possible.



Getting Press Coverage

There are a lot of resources online about writing a good press release, but hundreds of thousands of press releases are received by online and print publications each day. Do not get discouraged if you submit a press release and are unsuccessful. If you have a personal story, try reaching out to the media directly with your personal perspective and you might have success. Do not forget to include a call to action for your cause.

Work your connections. Maybe a friend of a friend's mother works with someone at a newspaper or radio station. Do everything you can to find someone who can help put your cause on the map.

ⁱ <http://www.advocatesforyouth.org/publications/publications-a-z/2229-youth-activists-toolkit>

ⁱⁱ http://www.unicef.org/evaluation/files/Advocacy_Toolkit.pdf

ⁱⁱⁱ <https://www.t1international.com/charter>

^{iv} http://www.advocatesforyouth.org/images/stories/Activist_Toolkit_jpgs/EscalationofTactics.jpg



Case Study: Law for People with Diabetes

Estefi, person with type 1 diabetes in Argentina

Issue: People with diabetes in Argentina often have to pay for a private health care provider, which is expensive and unaffordable to many. In Argentina there is a law (Nº 26.914) which should protect people with diabetes. The law states that the government programme should provide all the things that we need to treat our diabetes (insulin, test strips and supplies) for free. In reality, this does not always happen.

Diabetes associations offer advice and guidance on the scope of this law and the rights to health care that people with diabetes have so they can make the appropriate claims. As young people we wanted to do more to ensure the law was being enforced.

Action: We started talking with some politicians from different locations in Buenos Aires. We made an appointment with each of them, and we took with us an intention letter to have them sign it. We realized that sometimes young people have a louder voice to ask for something, and we wanted to fight for our rights and for those people that cannot easily do it.

After talking with five or six politicians, we wanted to go to a higher level. We set up meetings with provincial and national ministers and deputies. We were knowledgeable and educated about what we were asking for. We made sure that we knew our rights and we set goals along the way. This allowed us to get moving, knock on doors, and speak out.

Outcome: Fortunately, we reached a compromise with the National Health Ministry to ensure that they enforce the national law through state control mechanisms to ensure compliance by all health officials, the state, social work, etc. This will allow all diabetes care to be covered by the government programme in practice. So instead of just words, the law will be put into action.

On the one hand the situation is better than before, but on the other hand we will keep working and insisting on access to diabetes supplies to make it a guarantee for everyone!

4. Evaluate and Celebrate



4.1 Ongoing Assessment

Now that you have taken some action, it is time to reflect. You might be tempted to go full steam ahead once you have made your plan. That can be a good thing, but it is best not to let too much time pass before reflecting on how effective your actions have been when trying to reach your goal. Within your advocacy plan you have a section outlining 'how we will know when we have succeeded', and you should have similar measures set for each activity you undertake.

It is important to build ongoing self-assessments and 'sense checks' into your advocacy plan. This will allow you to take pause and ensure that your activities are aligned with your objectives and goals so you can stay on target. Record what has gone well and what has not gone as well as you hoped, and over time you will have a catalogue of activities to draw upon for guidance about the best way forward when addressing new goals and challenges.

Your assessment can be as simple as stopping to make notes after each activity or event to evaluate whether it was effective based on your pre-set measure of success. It should involve the question 'Did this help us move towards achieving our goal?'

For example: You tried to get 5,000 signatures on a petition about reinstating the clinic budget to present to a government official, but only got 3,000 signatures. It is time to think about the reasons for this shortfall and what you would need to do to achieve the goal in future.

“When everything feels like an uphill struggle, just think of the view from the top.”

Unknown

4.2 Learning & Improvement

In order for any evaluation process to be meaningful and to result in tangible change and improvement, there needs to be genuine acceptance of responsibility to make changes.

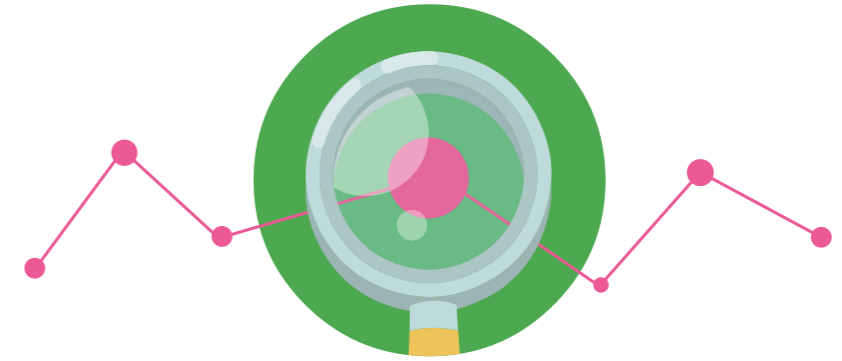
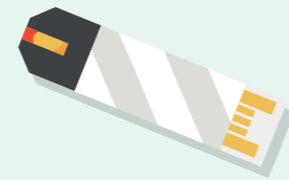
4.2.1 Evaluate your Advocacy

It is time to evaluate your advocacy with an intent to improve the areas that you and your team can control and influence. Some factors will be out of your control, so try to stay focused on things you can change.

Practical Evaluation Exercise Questions:

1. Did your advocacy activity produce the desired results or did it fall short in some way? If so, why and how could this have been avoided?
2. Are your techniques working? How effective are they?
3. Were advocacy skills and resources applied in the most effective way?
4. Are you reaching your target audience?
5. Are you still sure that your target audiences, messages and communications channels are the most appropriate for achieving your objectives?

Sometimes your actions might not show results for a while and it will take time before you can fairly evaluate your advocacy plan and process. It is still crucial that improvement opportunities are identified on an ongoing basis even if they are not necessarily able to be implemented right away.

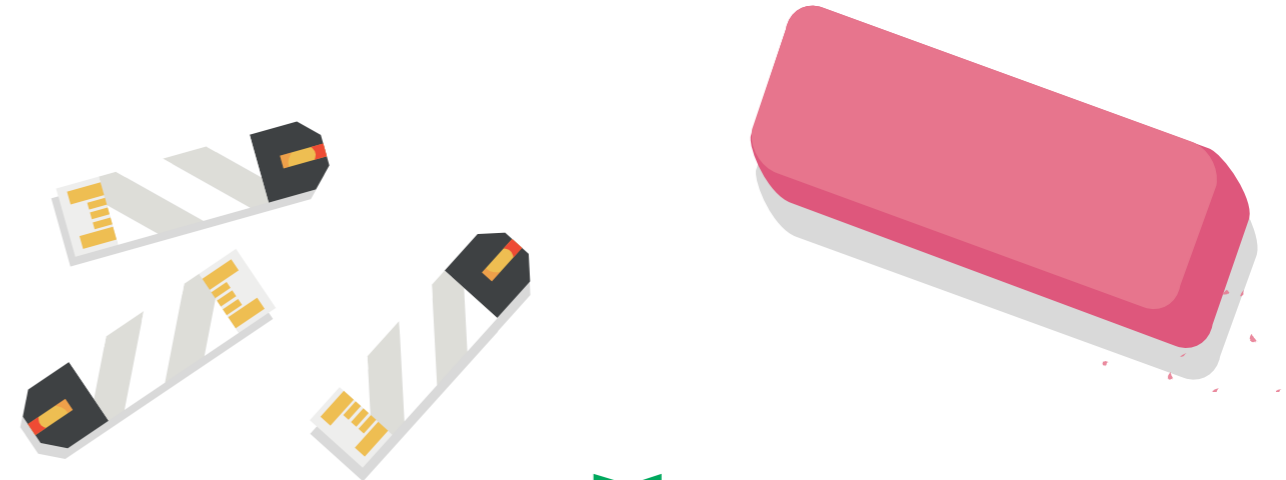


Similarly to when evaluating the process, knowing the real impact of your advocacy might take time to truly show itself. Indicators of success can be difficult to find in advocacy because many factors and situations are often responsible for social change. But measuring and evaluation is possible. When you set your objectives you will have decided the ways you will measure if those objectives have been achieved, so now is the time to look back at that. Setting specific, measurable and time-bound goals will make the evaluation process more straightforward and reliable.

Evaluation is about gathering and considering both positive and negative feedback. This will help you to prove that change is happening, and work on areas where change is not happening.

For each objective you will want to consider whether you need hard data or anecdotal evidence to show that your target audiences have changed their attitudes or behavior. The measures and feedback that you will use and assess can be qualitative (words and opinions of those affected) or quantitative (numbers); a mix of both is best.

Take the occasional opportunity to request that stakeholders complete surveys and provide feedback. This will be a goldmine of information to use in your continuing advocacy efforts.



4.3 Sharing & Collaboration

Always take or make opportunities to share your learnings and best practice with other individuals and organisations that are also pursuing advocacy. You never know when you might benefit from information they also have to share. Teaming up with another movement may be the key to your success. Make sure to communicate regularly and establish partnership agreements when necessary so that expectations are clarified between you and your partners.

Consider what additional skills may be required to help with reaching milestones. This is especially important once you have started to carry out your action plan because gaps in resources and skills will become obvious. Again, working with partners might help you to fill some of these gaps. For example, maybe a partner organization has a legal expert on their team, so they can help with legal messages in your advocacy plan. Another partner might have something as simple as a copy machine that they might let you use if you are working well together.

4.4 Barriers & Roadblocks

Do not get discouraged if you have come up against some really tough challenges and cannot see a way forward. Even if you cannot get past a roadblock, you will learn something from the experience.

Consider what additional skills may be required to help with reaching milestones. Get in touch with us and the diabetes community to discuss your roadblocks. Join our Facebook group: **Diabetes Access Advocacy (T1International)**ⁱ and share your challenges. Together we can work on breaking down barriers.

“Activism is something that no one can fake. You get angry. You cry. But you never throw in your towel, because that anger is what is propelling you to further action.”

Leymah Gbowee

4.5 Celebrate Victories!

Keeping a record of what has been successful means you can share the change you have made with others. It will also be a much needed reminder and confidence boost when you are feeling overwhelmed or let down by barriers in the process.

Take time to take stock and celebrate a milestone reached, even for a short time in the middle of your action plan. This will help motivate everyone involved and inspire them to keep going with the hard work.

This recognition will encourage and empower everyone to remain focused. Your successes will provide data and experience when tackling your next advocacy goal and beyond.

And always remember that the fight is never over, so set your next goal!



ⁱ <https://www.facebook.com/groups/T1InternationalAdvocacy/>



Kenya

Case Study: Access to Glucose Meters and Strips

Mbolonzi, person with type 1 diabetes in Kenya

Issue: In Kenya, the price of diabetes supplies is unaffordable for many people, especially blood glucose machines and strips. The cost of those items varies widely from region to region and from one pharmacy to the other. Blood glucose machines cost anything from \$35 to \$60 USD, and strips range from \$25 to \$35 USD for one box. This is not attainable for most Kenyans, with more than 40% of people living below the poverty line. Some people have blood glucose machines but they cannot afford a regular supply of testing strips. This makes whatever machine they have useless. Therefore many people do not test their blood as frequently as required. The consequences of this are dire and diabetes complications become inevitable.

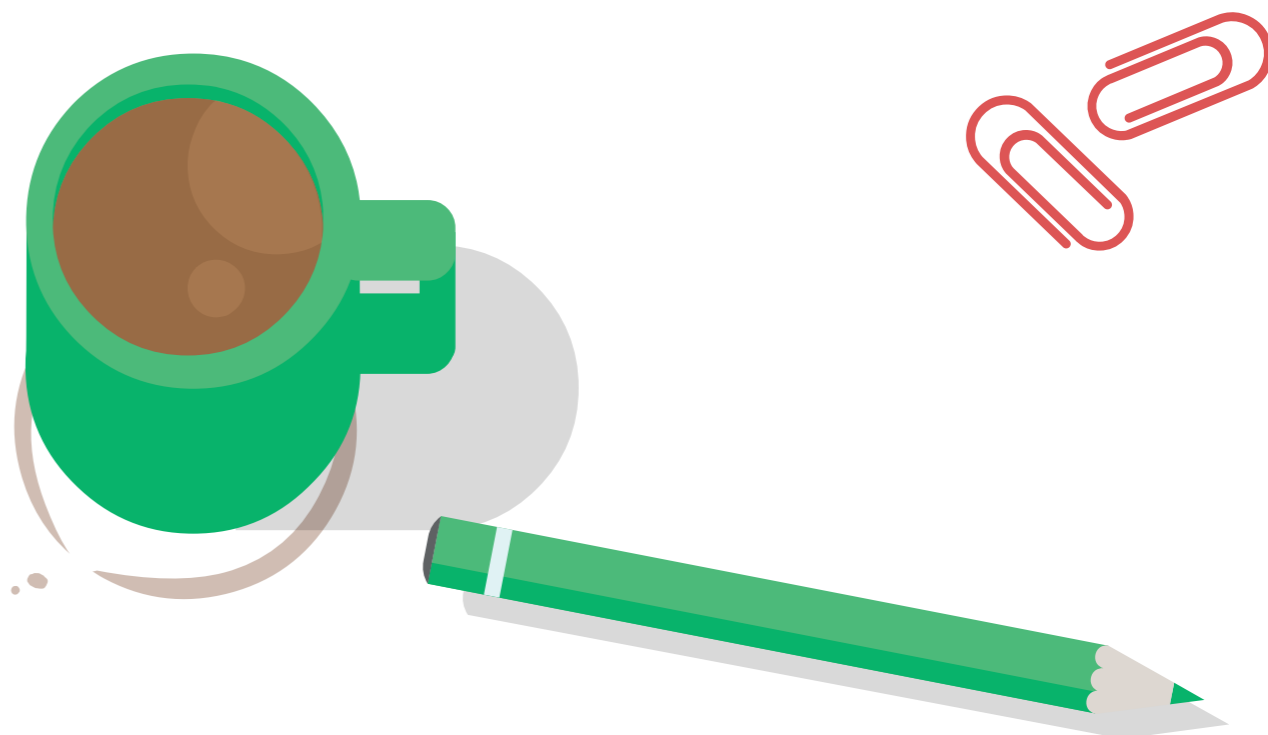
Action: I founded an NGO called Diabetes Awareness Prevention Management Kenya (DAPMK) and as the Chair I worked towards an agreement with Accu-Chek, a major brand of blood glucose machines and strips. I started by emailing the Accu-Chek team to set up a meeting. I also made many persistent requests to meet with the Head of Marketing in the Africa region. I made myself available so that it was hard for them to say no, and finally was introduced to the Regional Manager of the East Africa Region. She in turn put me through to the Distribution Command Execution Manager (DCEM) in Nairobi to meet and discuss the situation.

To further ease the burden of Kenyans living with diabetes regarding the price of blood glucose machines and strips we at DAPMK are engaging the government to tax exempt diabetes management suppliers, which would decrease the cost of the items even more. I am engaging the Kenya Revenue Authority together with Treasury to see if this tax exemption can be included in the national budget. DAPMK also plans to do an open letter to the President soon, from people with diabetes in Kenya. We will work to gain press coverage for this letter to help influence decision-makers.

Outcome: My meeting with the DCEM was very successful. She eventually agreed to create an account for us directly with the distributor, so that we would not have to buy from the pharmacy that would mark up the price by more than 30%. I was able to tell her that there would be at least 50 people willing to buy the blood glucose machines and test strips if the price was lower. Knowing they can sell more of these items, we are now allowed to get the products at a much lower cost.

As a member of DAPMK, someone with diabetes is now able to get a blood glucose machine at \$15 and a box of 50 strips at \$14.50. Accu-Chek have promised to have a constant supply of testing strips available at the reduced rate for our members. This is a good result because now these items are more affordable and Accu-Chek will have more customers. We managed to find a win-win for both sides.

We are already seeing our members buy the Accu-Chek Active blood glucose machines and strips because the price is now more within reach. That means they are able to better manage their condition because they can now afford to test their glucose levels at home.



5. Useful Tools



5.1 Good Practice Principles Checklist

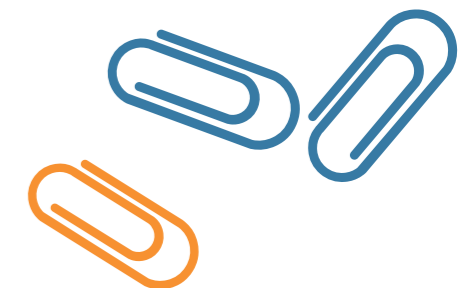
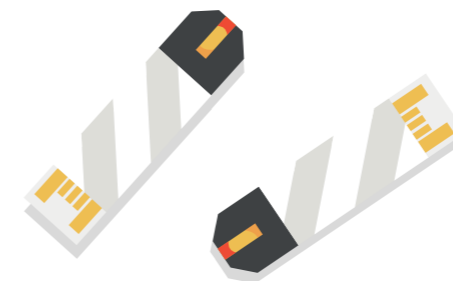
This list, based on one from Tearfund, includes important things to think about when starting & planning your advocacy.

Accountability

- Have the advocates acknowledged and assumed responsibility for the advocacy messages and actions?
- Do the advocates and the affected communities (if different) 'own' the advocacy initiative?
- Are the advocates accountable to the affected communities for their advocacy messages and actions?
- Have the advocates ensured that nobody has been marginalized in decision-making during the advocacy process?

Legitimacy

- Do the advocates have authority to advocate?
- Are the advocates involved in, interested in or affect by the issues or do the advocates have a genuine reason for advocating on behalf of someone else?
- Are the advocates clear about the basis upon which they are entitled to advocate?
- Are the advocates committed to the issue, and the people involved for the long term?



Participation

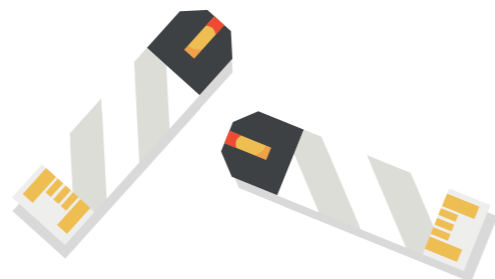
- Has everyone interested in and affected by the issue been given the opportunities to be consulted, included and have their views considered throughout the advocacy process?
- Are those affected adequately aware of the risks involved?
- Are they proposed advocacy messages and actions acceptable to those affected?
- Are those affected being kept informed of progress?
- Is capacity being built for people interested in and affected by the issue to advocate for themselves?



5.2 Other Advocacy Toolkits

When creating this toolkit we researched other useful advocacy resources and toolkits. There is a lot of information out there, including country-specific diabetes advocacy, advocacy for other health conditions, and youth advocacy tools – to name a few. We have done our best to ensure that we are not reinventing the wheel. We discovered useful elements from many of the resources and tried to tailor our content to the diabetes access cause to make it as useful and practical as possible.

We have created a spreadsheet with other resources that might be helpful to your efforts. You can access this sheet in our Facebook group: **Diabetes Access Advocacy (T1International)**ⁱⁱ.



5.3 Legal Resources & Regulations

It can be challenging to know where to start when adding a legal element to your advocacy work. It is always best to have support from a lawyer if you are doing legal advocacy that is complex or risky. However, you can still incorporate elements of the law into your advocacy plan's key messages. At the very least our resources should help you start to think about these elements so you can explore them in future advocacy.

It is helpful to approach this on three different levels using law from each category: international, regional or country, and local/community.

5.3.1 International Law

If your country supports these, use agreements like The Universal Declaration of Human Rights, The International Covenant on Economic, Social and Cultural Rights, and the World Health Organization Constitution to help support your case for the right to health and access to medicine.

5.3.2 Regional Law

Keep an eye on agreements and efforts made by regional bodies like the African Union (www.au.int), European Union (www.europa.eu), or the Association of Southeast Asian Nations (www.asean.org). You can use statements and coordinated regional efforts to push for your specific cause.

You may also find regional organizations and groups (like www.myafricanunion.org) that encourage governments to follow up on their commitments. These groups could make useful partners and may already have good knowledge of laws and legal systems that can be referenced or used in your advocacy work.

5.3.3 Country/State Law

For starters, explore your country's constitution and see if there is reference to anything health-related. Read up on any agreements or promises made by the Ministry of Health or related governmental body so you can use the contents of any agreement to hold them to account.

Somewhere like the USA, where each state has its own laws related to access to health and medicine, things can get a bit trickier. You will want to understand the law of your state as best you can and any propositions to make access to medicines easier.

No matter where you are in the world, try to start a dialogue with your local politician or representative (Member of Parliament, Congressman, State Representative, etc.) to ensure they can hear your messaging and the benefit to them if they push your cause within government.



5.4 T1International Resources

T1International has information and documents that can be useful to help you meet your advocacy objectives and goal.

Some of our resources include:

- Insulin and Supply Survey data
- Type 1 Diabetes Access Charter (available in 10 languages)
- Rights of the Child with type 1 diabetes document
- Rights of the Person with type 1 diabetes document
- Cape Town Declarations
- Videos on our YouTube channel
- Various infographics

Visit www.t1international.com/resources to explore what is available.

We will make updates and add more useful tools and information as the toolkit is put into action.

5.5 Ongoing Support

Please join our Facebook group called **Diabetes Access Advocacy (T1International)**ⁱⁱ. This will be a space to share success, ask questions, support each other in our efforts, offer feedback on the toolkit, and share tips and strategies.

We will also add additional information and resources that we couldn't fit in the toolkit such as a Project Plan, Communications Plan, and Risk Log.

We encourage you to reach out to our team at contact@t1international.com if you have any other questions or feedback about this toolkit.



“Unless someone like you cares a whole awful lot, nothing is going to get better. It's not.”

Dr. Seuss, *The Lorax*

ⁱ http://tilz.tearfund.org/en/resources/publications/roots/advocacy_toolkit/

ⁱⁱ <https://www.facebook.com/groups/T1InternationalAdvocacy/>

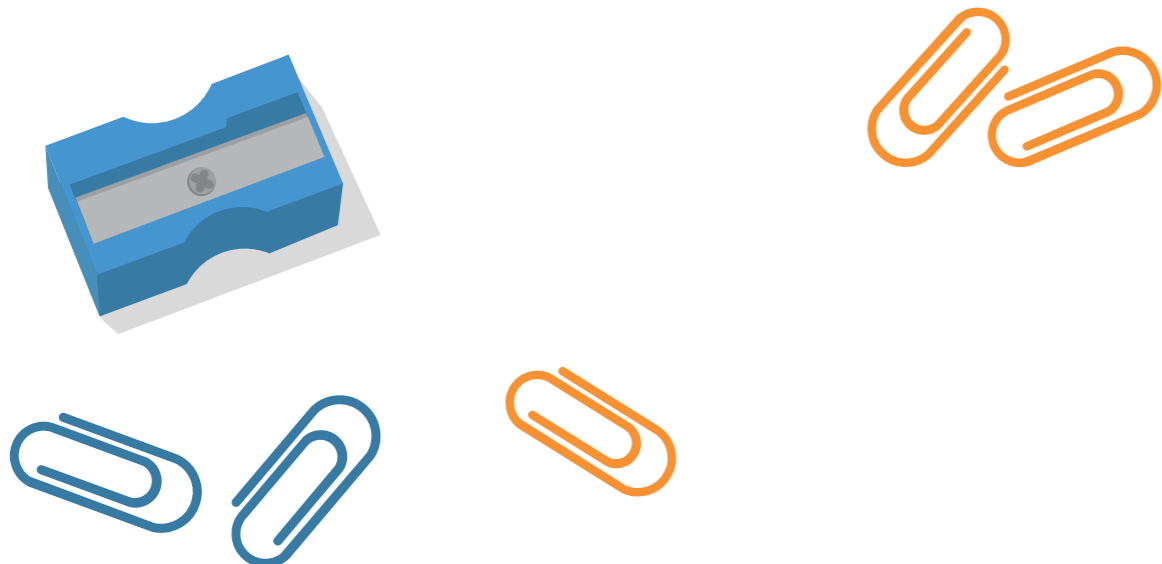


Germany

Case Study: Access to Continuous Glucose Monitors

Jan, person with type 1 diabetes in Germany

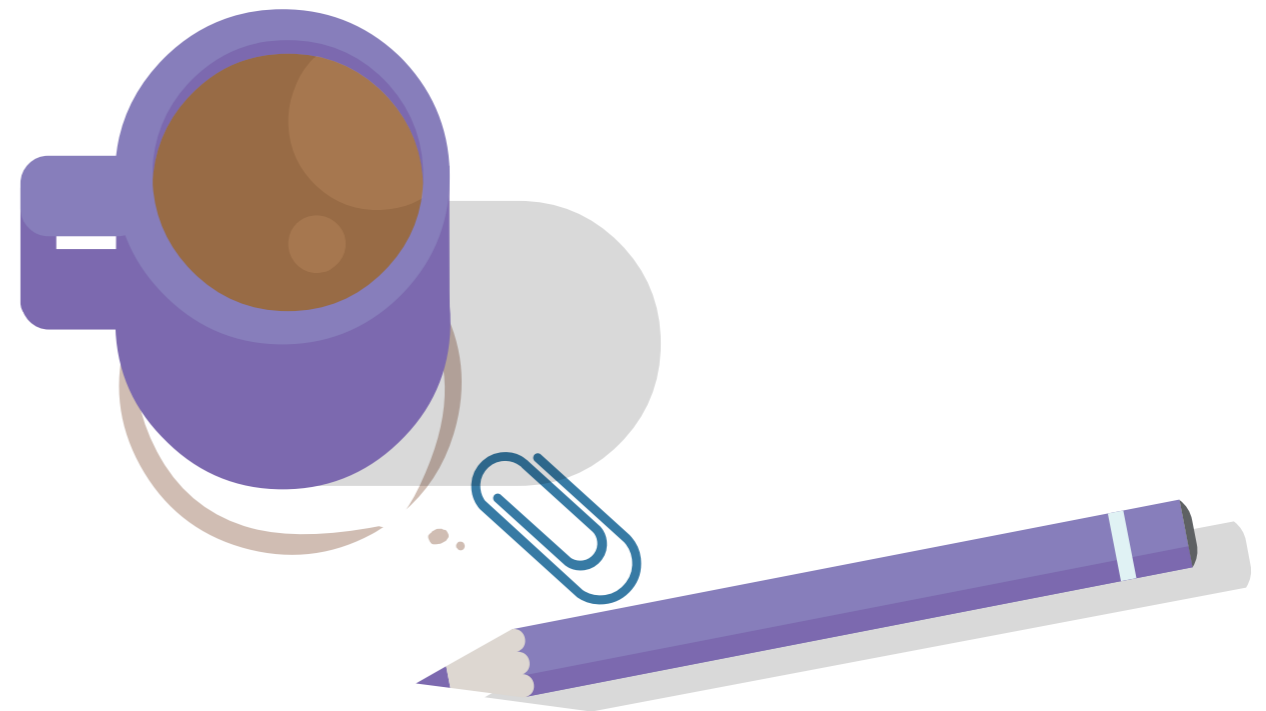
Issue: In Germany, everyone has a right to medical devices covering their special needs. When the Continuous Glucose Monitor (CGM) came to Germany, it was seen as a “new examination and treatment method.” This means that it could only be covered by health insurance if someone was facing death or dangerous situations and the medical device is the only thing that can help. Pregnant woman sometimes got a CGM to secure the life of the unborn child, or people who often had severe hypos. We wanted everyone with diabetes to be able to access this technology.



Action: Our diabetes association in Germany, along with people with diabetes, doctors and the nurses organization started a platform around the time of our last parliament elections which is called Stop Diabetes – Now! Through the platform we enabled people with diabetes to lobby their MP through sending them our claims and asking for a personal meeting. We also asked people to send a postcard to Angela Merkel, the Chancellor of Germany.

A lot of people connected with their MP in meetings and put the issue on Angela Merkel's radar. We also tried to make public how many people in our Parliament have diabetes to get media attention. This led to a national diabetes plan being part of the discussions when the government was forming a coalition. We secured a close contact to an MP of the government coalition who was in favour of a national diabetes strategy. We lobbied him to show that CGMs are a key factor to enhance the quality of life for everyone with diabetes and a key factor to better and steadier blood glucose levels. We explained that this leads to less complications and less costs to the government.

Outcome: The government passed legislation stating that people with diabetes (type 1 and type 2) can get a CGM if they cannot reach or hold their blood glucose target range without a CGM. The target range of blood glucose is something you can set yourself with your endocrinologist. For example, if you set an HbA1c of 6.5 as the target and you are not getting an HbA1c of 6.5 without a CGM, you may get one provided by the government. You just need to prove that you tried everything to improve it with the normal therapy. This means many more people have access to a CGM in Germany now.



Anyone can be an advocate...
you just have to practice.



Do you already consider yourself an advocate, or are you new to type 1 diabetes advocacy? Either way, this toolkit was made for you. We hope that it will be the beginning of your ongoing diabetes advocacy to improve access for people with type 1 diabetes. Inside you will find information about the steps in an advocacy plan, like setting goals and developing a strategy. The toolkit also covers taking action, celebrating successes, as well as analyzing and evaluating your advocacy. So let's get started, advocate. Together we can change the world for people with diabetes!



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