Empowering and championing yourself leads to advocating for the larger community. This toolkit is meant to take you through a journey that we hope will help you see the strength you possess and give you actionable pointers to convert that into meaningful impact and change. This toolkit is not meant to be a rule book – but rather a lose guideline that will offer you ideas and perspectives that you can mould into your personal advocacy style.
FOREWORDS

part 1

Become a Type 1 Champion – One voice is an anthem

part 2

Meaningful Engagement with the community – Better Together

part 3

Working with Stakeholders – Addressing issues at a policy level
Type 1 Diabetes is—frankly— all-consuming for those who live with it—and in spite of all that is available, whether that be modern insulin, technology, adequate support—life can be tricky—as there are ups and downs that no medical textbook teaches us clinicians—yet the one living with T1 Diabetes experiences.

If you then add in the factor that to many, many people such support are mostly a pipedream and a distant wish, life is even more tricky.

To help ensure that we can give Type 1 Diabetes people the best chance to flourish in life, we need awareness—and a key component of that—as ever—is with advocacy. Not only from clinicians—but from those with the lived experience as they tend to be far more powerful, impactful and reach the ears of those who can help with sustainable change.

This tool kit from Diabesties is an excellent way how to approach the issue of advocacy—and breaks the mould that to do advocacy one needs to fit a certain stereotype. Advocacy can be done by anyone—and this toolkit suggest ways as to how embrace this.

As an African proverb goes: “Family must look after family”. And no better example of the community engaging more in advocacy to help each other.

Professor Partha Kar
Consultant Endocrinologist
Portsmouth Hospitals NHS Trust
National Specialty Advisor, Diabetes, NHS England
GIRFT Co-lead, Diabetes, NHS Improvement
I wish to congratulate you and Diabesties for bringing out the Advocacy Toolkit. This is a very important step for everyone with Type 1 Diabetes and especially for children with this disorder. What I liked about the Toolkit is its simplicity. The points are made with very few words or written matter, but with very powerful images. The concept of uniting for a cause comes out VERY strongly. The use of effective colours, like pink, will attract children. I am sure that the launch of this Toolkit will be one more feather in the cap of Diabesties and Jazz. I cannot help admiring the passion with which Jazz and her team work for the cause of Type 1 Diabetes. As always, my very best wishes to the whole T1D community.

Dr. V. Mohan  
Chairman and Chief Diabetologist,  
Dr. Mohans Diabetes Specialities Centre
ADVOCACY FOR US, IS THE PROCESS OF supporting & enabling

Have their voices heard.

Express their views and concerns on a situation, policy or programme.

Access information and services.

Defend and promote their rights and responsibilities.

Explore choices and options

Spread Awareness in contextual settings

Sensitize the public with perspectives
Before we begin..

what is advocacy?

“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 with other people and organizations to make a difference.
“YOUR VOICE CAN MAKE A DIFFERENCE. JOINED WITH OTHER VOICES, IT CAN BE AN ANTHEM!”

Every country has different issues in Type 1 Diabetes care. Lived experience is a crucial piece of the puzzle that is often overlooked by decision makers. We urge you to use your experiences to design solutions to issues you may face in your country.

why is this important?
To address inequity, disparities and injustice.

To change and challenge attitudes, power and social relations and institutional functions.

To expose a problem that needs to be addressed by policy makers, service providers and managers.

To persuade or influence decision makers on an issue.

To sensitize the public to be more responsive to the needs of a constituency, group, or community.

To provide a solution to a problem that affects a constituency.

To ensure that people, particularly those who are most vulnerable in society, are able to have their voice heard and defend and safeguard their rights.
choose your cause—
In this case, the cause chose YOU.

In some ways, your cause has chosen you. Getting a T1D diagnosis can be hard at first – but it has also given you this unique opportunity to do something larger than yourself. Leverage that into designing a purpose filled journey to go beyond the diagnosis and into the depth of society to make actionable change.
We know that there are several issues that need tackling – but you need to zero down on what truly affects you. Some of these questions may help you think about exactly what bothers you in the T1D arc and can help you pin point what really needs attention. Use your personal experiences as a beacon and then widen to what you may have ‘read’ and ‘heard’.

- What are you truly passionate about changing?
- What experience has shifted your perspective about the T1D healthcare system in your country? What did that make you feel?
- What is the T1D best case scenario for you? What is the current situation like?
- Use resources to help you think: Use the T1D Index (t1dindex.org) to learn more.

(Think back to personal stories and experiences or stories you have witnessed. What stirs you? What cant you take? What bothers you?)
Find your purpose

(Why are you advocating)

Think wide, but go deep. There could be many reasons you are advocating - but it needs to be structured. 1 step at a time.
Become a Type 1 Champion – One voice is an anthem.
IF YOU ARE SOMEONE LIVING WITH TYPE 1 DIABETES –

you are already a champion!

It takes a lot to think like a pancreas – and we applaud your strength and resilience. At Diabesties, we believe that as someone living with Type 1 Diabetes, you have a duty to your personal health and a responsibility to others in the community.
Self-Empowerment comes from self-education. Try to ensure you are well educated about the different topics under Type 1 Diabetes management and are achieving the best control you can. This not only ensures your health is in check, but it also acts as a source of inspiration to the community. If you feel like you need to better your understanding on a few topics, below are a list of resources that can help:
As someone living with the condition, you already know what it means to face the challenges this life throws at you. Now, we want you to look further. You may know what it feels like to get a hypo or hyper, but you may not know how it feels to struggle for access to insulin, or live without a fridge, or ration out supplies. We want to challenge your perspective here and help you widen your understanding of the different realities people face.
essental questions

- What does it mean to put yourself in someone else’s shoes?
- How empathetic am I?
- How can I better show empathy toward others?
- How can I learn more about others like me in different socio-economic brackets?
identify your key issue
MAKE A MIND MAP OF ALL THE THINGS YOU BELIEVE ARE GOOD IN YOUR COMMUNITY AND WHAT YOU DO NOT WANT TO CHANGE.
NOW MAKE A LIST OF ALL THE ‘HOT SPOTS’ IN YOUR COMMUNITY. THINGS YOU BELIEVE ARE NOT OPTIMUM AND WOULD REQUIRE SOME CHANGES.
FOCUS ON THE SECOND LIST AND IDENTIFY ONE OR TWO THAT YOU BELIEVE YOU CAN ADD INPUTS TO.
TRY TO ALWAYS THINK OF YOUR PERSONAL STORIES AND EXPERIENCES TO GUIDE YOU TO IDENTIFYING THIS.
Other questions to consider:
- What outcome would you like to achieve?
- What is realistic within available resources (e.g., time, money, personnel, knowledge, skill)
- How will you know you have achieved your goal?
Change doesn’t have to be big! We recommend you start small – one person’s life made better is also a worthy impact. Once you begin, you can then seek partners and leverage the power of multiple voices.
FIND YOUR ADVOCACY VOICE

Advocacy does NOT have to be boring.
We urge you to break that mind frame and really have fun with it. Let your personality shine through your message – it will, in fact, do more to bring attention to the issue you are focusing on. Ensure to use your unique perspective and story to add layers of lived experiences and create a strong and impactful narrative.
ACTIONABLE IDEAS: USE YOUR SOCIAL MEDIA AS AN EVOLVING STORY.

Have fun with your social media handles to bring attention to the issue at hand, with a creative spin!
• Use relevant hashtags.
• Tag relevant national/international bodies
• Use compelling images – quality over quantity
• Have an advocacy language that you maintain.
• Get creative and wild! There is no rules in advocacy – the mission is to get the message out
• Come up with creative slogans
• Use contextual and regional language – make it as close to home as possible for maximum efficacy.
• Collaborate with fellow advocates to gain more traction
• Always stay true to yourself and your message.
• Consistency – remember, this is a marathon and not a race.
• Engage with the community through comments, interactive sessions etc.
EXAMPLES OF SOCIAL MEDIA ADVOCACY

school awareness:

Act / Sustain / Measure impact
Meaningful Engagement with the community – Better Together

PART 2
AT DIABESTIES, WE STEER AWAY FROM THE TERM
‘giving back to the community’

For we believe that WE ARE the community. If not us, then who and if not now, then when?
“chapter heads”

Below are a list of actionable ideas that you can use to create movement and engagement within your community. Remember, you can adapt these practices in the best way you feel fit. Add your own flavour to these ideas to ensure a unique engagement opportunity.

We call these: CHAPTER HEADS
GETTING PEOPLE WITH TYPE 1 DIABETES TOGETHER.

This is a crucial first step which will allow you to build your network and set up your peer support group. Depending on which region, country you are from – this could be an easy task if people are willing and adaptive, or can pose with challenges if there is stigma prevalent around openly discussing the condition.

How to reach out?

We have found great success with:

- Reaching out to doctors to recommend their patients to you.
- Putting up engaging posters in pharmacy’s
- Social media – a sure shot way to get some traction and connect with people around you are.
- Word of mouth: Keep the chain continuing and you will find a few people through this.
helpful tips

When you approach new people with Type 1, try to always initiate the conversation with your own story. Tell them explicitly, “Hey, I am Type 1 too!” – we have found that this instantly breaks the ice and makes them trust the intention of your conversation.

Make it clear that you have no vested interests (pharma, branding etc.) and you just want to create a group where you can talk about your diabetes, learn from each other and celebrate each other.
COMMUNICATION WITHIN THE GROUP.

Now that you have your group in place, it's important to establish a communication channel. Depending on your country there will be different platforms available that can allow you to do this. Messaging groups are often the easiest and most efficient medium of communication.

- Running the WhatsApp / Signal / Telegram group
- Ensure ground rules of the group are set.
- There should be a welcome message when a new member joins.
EXAMPLE OF THE RULES/WELCOME MESSAGE:

All members are to adhere to the crux of the group which is community support for people affected by Type 1 Diabetes. All communication related to Diabetesties, T1D & Diabetes is welcome. Kindly note that all communication on the groups is not to be mistaken for professional medical advice. Medical advice should only be sought from a professional. Promotions, advertisements and marketing is prohibited. Abuse, hate speech, personal remarks & obscenity will be strictly dealt with.

THINGS TO KEEP IN MIND WHILE RUNNING THE GROUP:

- Ensure questions are answered
- Build a good relation and rapport with the members
- Be stern about misinformation that may be spread
- Never give out medical advice
- Add a unique Display Picture
- Maintain decorum in the group
- Use this to communicate about upcoming events
CREATE LOCAL TEAM

Now that the group is formed, identify people who will be willing to volunteer to raise the profile of Type 1 diabetes in your area and beyond.

A few qualities to look for in volunteers-

- Look for someone who is vocal about living with diabetes.
- Should be enthusiastic to spread awareness and advocate about living with the condition.
- Should be resourceful (has good contacts).
- Is willing to learn and educate others about living with diabetes.

After the identification of volunteers, hold an orientation with all the members of the team to delegate responsibilities. Discuss the mission and vision to ensure that everyone is on the same page.
planning events

Once the local chapter team is created, start planning events at least once a month.
(team can take a collective call on this) and design the activities of the event around that theme. For example- If the theme is Dialympics (Diabetes Olympics) and we are playing tug of war, it can be a competition between caregivers and people living with Type 1 diabetes. The message that can go out in the end is that a person with Type 1 diabetes is as strong and capable as any other non-diabetic.
TRY TO KEEP EDUCATIONAL ELEMENT IN ALL THE ACTIVITIES/ GAMES.

For example- if you are playing dumb charades, add diabetic words such as glucagon, hypoglycaemia, hyperglycaemia etc. and ask participants to enact these words. Once it is guessed, ask participants what it is or what it is used for. Inform them if they don’t know already. We have seen that a lot of the participants don’t know about a lot of diabetes terminology. Adding an educational twist to the activities can be a very engaging medium for people to learn.
Please ensure all the housekeeping details are tended to at least a week before the event. Here’s a checklist of all the things that needs to be taken care of:
Ensure that your funding is in place before organizing the event. It can either be funded by some organization / pharma / company or it can be collectively funded by all the participants participating in the event.
A few things to keep in mind while looking for a café is that it should have ample space for people to move around (if your activities require movement). It should ideally have a central location; if not, it should be approachable. Keep your permission letter with all your requirements mentioned—number of people expected to attend the event, for how much time will you be requiring the space, any specific requests such as putting decorations etc. and of course the date on which you require the space.
PARTNERING WITH CAFES

Start finding cafes at least 3-4 weeks prior your event. A lot of cafes partner for a good cause at minimal/discounted prices, so be very clear about the WHY with them. Ideally, book the entire café if you have a good number of participants or check if they have a private space that you can rent out for a few hours. If you are getting a good deal, ensure them that you will be organizing the next few events at their café. If you have a good social media presence, give them shoutouts and you can also recommend them to your T1D friends!
Get all the permissions (if required according to your country/state law) at least a week prior before the event. Amongst the volunteers, find someone who can videograph and click pictures of the event to document it. Video of the event can be circulated on social media to create traction and get more participants in the next event. Also, document all the activities/games played at the event. This document can act as a reference for designing other upcoming events.
For each activity, create a resource checklist. Get your resources organized at least 2-3 days before the event. Re-check everything on the day of the event to ensure that you have everything in place.
CONDUCTING DIAMEETS

Coming to the most exciting part after getting the tedious task of organizing everything for the event, DiaMeet is an energetic, full of life party for people living with Type 1 diabetes. Greet everyone with the biggest smile you have and a hug! Make them feel at ease as they enter the event.
ADVOCATING FOR THOSE WHO DON’T HAVE A VOICE
When ‘my’ diabetes becomes ‘our diabetes’

Each of us come from different backgrounds and some of us come from a greater place of privilege than others. Things that some of us take for granted, like simply being able to speak up and advocate, is unimaginable for certain sections of society. That’s often why, when advocacy is done, it’s done keeping in mind limited concerns and issues. It’s our responsibility is to ensure that all voices, even those who cannot speak for themselves, are taken into deep consideration. For inclusion is a right, and not a privilege for a select few.
Here are a few practical ideas you can implement to ensure that you get an informed understanding of ALL those with the condition:

- Focus groups with those from different backgrounds
- Ask them for their wish lists
- Prioritize what you can do and what you can't.
- Work with different sections
- Reaching the unreached
- Understanding the shortcomings
- Contextualising and adapting
Qualities of a chapter lead:

A good leader is one who is:

- Empathetic, not sympathetic
- Motivated and inspired
- Able to lead with moral authority
- Able to deploy resourceful, yet sustainable practices
- An efficient manager and self-learner
A fixed slot in your schedule to dedicate time.

Regular weekly/monthly team meetings to monitor progress and address issues.

Regular brainstorming sessions, constantly updating and creating mind maps.

Change doesn’t occur overnight; neither does it happen alone! You need to remember your why, that is your purpose and motivation to advocate for the cause, and let it guide your actions. A commitment is required however small it may be to instil change. Some ways to instil this commitment and hold yourself accountable are:
get the community involved

- Get your T1D group
- Approaching doctors - the practical list
- collaboration not confrontation
- plan your activities (list)
wider strategies for advocacy and outreach

- Get your T1D group
- Approaching doctors - the practical list
- Collaboration not confrontation
- Plan your activities (list)
working with stakeholders – addressing issues at a policy level
Sometimes, what can get lost in the journey, is the person as the center. Try to steer back to the center, and always focus on the people and the stories to further your cause. With that, add on data and statistics to make a winning argument!
what makes an effective diabetes advocate?

The fact that you are someone who is living with the condition you are advocating for, already makes you an effective diabetes advocate. Below is a checklist that can help you convert that passion and fire you have for the cause, into strategic and systematic action:
THE HOMEWORK (RESEARCH AND DATA)

Before we get into any kind of action, one must put in the pre-work it needs. At Diabesties, we believe that advocacy is strongest when its backed by data.
setting goals requires an in-depth knowledge of the topic, based on the latest available research into the local, national or regional situation
THE AUDIENCE (WHO TO ASK)

it is key to understand how the decision-making process works and which stakeholders can support your advocacy goals.
THE TASK (YOUR ADVOCACY AGENDA)

some activities are more appropriate than others, and crafting strong advocacy messages is an art in itself
Policy makers and members of parliament need numbers and figures to identify the need more clearly. Go prepared with your figures and details. An effective diabetes advocate knows there cannot be advocacy without data, because data provide the essential background information to help place an issue in context.
quality over quantity

Never compromise on your data and the sources. Find credible and reliable data from reputed sources.

Use the T1D Index (t1dindex.org) to learn more.
There are several data points that you can use – but sometimes an overwhelming amount of data can also lose the impact of your ask. We have compiled a list of data points that we feel work best in furthering your message. Feel free to add or subtract from these to the context of your pitch:
before you draft..

Do your research, The T1D INDEX (t1dindex.org) is a solid starting point.
Use it to discover the current burden of diabetes, its development over recent decades and projected future trends. It will provide you with:

- Diabetes prevalence estimates for your country
- The estimated diabetes prevalence over the past 20 years, based on the best available data
- A view on whether your country is on track to achieve the World Health Organization’s target of a 0% increase in diabetes and obesity prevalence by 2025
- The projected prevalence for 2045
- The evolution of diabetes-related mortality and whether your country is on track to achieve the Sustainable Development Goal (3.4) of a 30% reduction in premature mortality from non-communicable diseases (NCDs) by 2030
- The direct financial impact of diabetes in our societies
Along with knowing the data points mentioned above, it’s also important to be aware of everything your country has done in the past about Diabetes. Have there been national guidelines published? Has there been access drives? Have any policies been passed relating to NCD’s? Does your country have a diabetes plan? The responses to these questions will give you a wider understanding of the state of healthcare in your country. It will also help you close in on keyhot-spots and gaps in the current action plan. These responses can also provide powerful evidence to support your work and help you channelise your advocacy plan.
THE ASK:

Your advocacy goal is the ultimate outcome you hope to achieve.
It should be aspirational and ambitious, something your stakeholders can easily understand. It is typically long term and not necessarily measurable. The most motivating goals are those that you are not fully certain you are able to achieve, so do not be afraid to be ambitious.

GOAL SETTING

The first step to change, is figuring out what you want changed. Use the research and data you have collected to formulate your goal.
bullseye focus – one is better than none
Your advocacy needs to be tightly focused on a specific issue to be the most effective. One common error in advocacy is to focus on the problem or a very broad topic such as “improved health care for stroke patients”. The problem with this is that when you don’t request a specific change, it is easy for decision-makers to agree but not do anything about it.
FOCUS ON A SINGLE GOAL

Trying to achieve many goals at once can also be difficult as it is hard to get a clear message. Go back to the data and identify what is of utmost priority. This will help you advocate for a very specific change. For example, you might want to advocate for increased access for Type 1 Diabetes Education, but the specific change you need is for the government to fund Type 1 Clinics in all civil and government hospitals.
1. To obtain funding for a FAST campaign in my region/state/country
2. For government to develop a diabetes strategy that will improve diabetes services
3. To establish a Type 1 Diabetes clinic in your district
4. To have formalised professional development Type 1 Diabetes education for General Practitioners at a rural scale.
set your goal

Here are some questions which can help you set the right goal:

- What do you ultimately want to achieve?
- Is there evidence that suggests the change you want will impact people living with diabetes positively?
- Does the change you want to achieve affect national or a local health policy?
- Is there a chance that additional funds will be dedicated to changing the situation you want to address?
- Is there any data indicating that the change you want can be cost-effective in the medium or long term?
- What is your capacity to address the challenge?
- Do you already know someone who could support you?
- What opportunities exist to influence the issue?
THE AUDIENCE:

Identifying the target audience of your advocacy campaign is imperative to designing a successful agenda.
YOU DON’T NEED JUST ONE TYPE OF AUDIENCE!

Think wide and out of the box about the people you want your message to get through to. Along with traditional audiences like policy makers – think of other influential people who you think might be able to advance and amplify the agenda.

Some examples of the same:

- Government Representatives
- Members of parliament
- Celebrities
- Corporates
- Health Care Professionals
- Unions
- Youth Groups
THE TASK:

Once you have identified your goal – it’s time to put it into action!! Setting your advocacy agenda and creating your message are the next steps.
YOUR MESSAGE IS THE FACE OF YOUR ADVOCACY AGENDA – TAKE TIME IN CRAFTING AN IMPACTFUL ONE.

The response from your target audience, your future engagement with advocacy and the success of your strategy entirely depends on how good the message is. You therefore want to dedicate as much time as is needed to craft the best possible message.

A good message needs to facilitate communication with your stakeholders. It has to be easy to understand, straight-forward, impactful and easy to remember.
Include data that highlights the extent of the issue and an example of it, such as a testimonial or case study. If you are using someone’s story for your advocacy messaging, make sure the person signs a consent form allowing you to use their story.
the call to action

your target audience needs to understand what you need them to do
the reasons for change

include all evidence that shows the potential positive impact (especially human and financial) of the actions you are requesting
the deadline:

to make sure you can achieve your objective in time, you must give your target audience a timeline for them to act
advocacy messages are not universal – a great message for one stakeholder may not be the best for another.

You must put yourself into your target audience’s shoes and consider the type of evidence and information most likely to impact them. For example, policymakers tend to react more to messages using evidence on the financial impact of the issue you want to address, while the general population is normally more touched by personal stories.
you need to tailor your messages depending on the channel you will use to deliver them

In-person interactions are a powerful way to share your messages but can be limiting when it comes to sharing evidence in a simply way. Written communications and social media, on the other hand, are less direct but offer the possibility to use tools that facilitate communicating evidence, such as infographics, drawings or charts. Regardless of who you are targeting or which channels you are using, make sure the evidence you use in your advocacy messages is simple to understand.

Ask researchers or anyone in your team who is good with data for support in this task. Feel free to test your messages on the people around you and assess how easily they understand the evidence.
DELIVERING THE MESSAGE:

The most powerful message won’t be convincing unless it is delivered by the right messenger.

Messengers need to be credible, charismatic and have the capacity to communicate clearly and passionately the need for change.

Tip: Using people with lived experience as the face of your campaign can drastically help raise the profile.
Be creative and liberal in the way you plan the activities for your advocacy agenda. Different types of activities will resonate with different types of audiences. The message stays the same, the way its conveyed varies.
Different types of activities will help you achieve different aspects of your objectives, so the best way is to combine a variety of initiatives to maximise your chances of success. Some of your activities will have to focus on raising funds to allow the implementation of your advocacy strategy, connecting with researchers to have access to the latest evidence, or networking to identify supporters for your advocacy goal. Others will be more directly linked to delivering your message to your target audience – which can include organising online or face-to-face events, engaging in meetings with policymakers, or developing media or social media campaigns to promote the evidence you have gathered and the need for action.

When planning your advocacy activities, it is very important to integrate online and offline initiatives as much as possible to engage your audience and deliver your messages. While advocacy has traditionally happened offline, social media platforms have provided advocates with a very powerful tool to disseminate their messages to a wider public and recruit more supporters to their goals.
Depending on the type of target audience your activity is intended towards, you will need to tweak your approach. You may have a different flavour for a social gathering than you would for when you’re meeting members of parliament. The idea is to contextualise your activity for that particular group – keeping the passion and the message the same! Irrespective of the audience, it’s important to stay focused and respectful. Optimise the allotted time, be well prepared with your resources and go over the flow in advance.
A quick checklist for you to go through before implementing any of these activities for particular target audiences:

Understanding your audience: a checklist

- They are very busy and have tight schedules.
- Key priority is image building and profiling
- Populists by nature of the job
- Know their language
- Research on how to present yourself
- Align your dressing code with the parliamentary etiquette
- Be brave, precise and to the point
- Be persistent and passionate
some more tips:

a) Have a well-pitched message with data (evidence).
b) Convince them on the benefits to the country.
c) Timing (when and how, assess, this varies).
d) Identify relevant structures or committees.
e) Identify an ally within the structure/committee and hold discussions as part of background search.
f) Embrace diplomacy and negotiation skills.
g) Avoid situations and discussions that may put you in a difficult situation like providing a hand-out as an enticement.
h) Depending on your assessment, being accompanied by people you are advocating for and with like older persons, women, Persons with Disability, a business group with a short and moving speech could be a plus. Avoid using children in such situations, unless they have been involved using child participation principles and ethics.
i) Be courteous but assertive.
Advocacy has no rule book. We hope this guide has helped you understand different facets of what is possible and opened up your mind to the scope of what can be done.

Remember, the most important bit of this journey – is action and impact oriented work.
be patient, be persistent & be passionate!

All of us at Diabesties wish you all the best for your advocacy journey – "You are Type 1 of a Kind!"