

Experts By Experience

Involvement Handbook

Sadly, Alister died before the launch of this handbook, but he was part of the process which brought our learning together. As a team, we wanted to dedicate this first edition in his memory.

Alister summed up all that we are about in a few words. "To see other people who have been inspired to go on and inspire others is phenomenal"

*Alister Ferguson
1958–2016*



CONTENTS

Welcome

Why do we need a handbook 8

What is an 'Expert by Experience'? 10

Pathway's Expert by Experience Charter 14

All the important stuff: rules and policies 20

"Being an Expert by Experience acknowledges that lived experience is as valuable as clinical/professional expertise. It provides me with the opportunity to use my experiences to improve services and feel support, respected and listened to as a person.

This has had a massive impact on my recovery, my confidence has grown, my skills improved and I now have hope for the future. I feel empowered to make a difference with a job that I love and positive personal relationships. I truly believe that becoming an EbE saved my life.

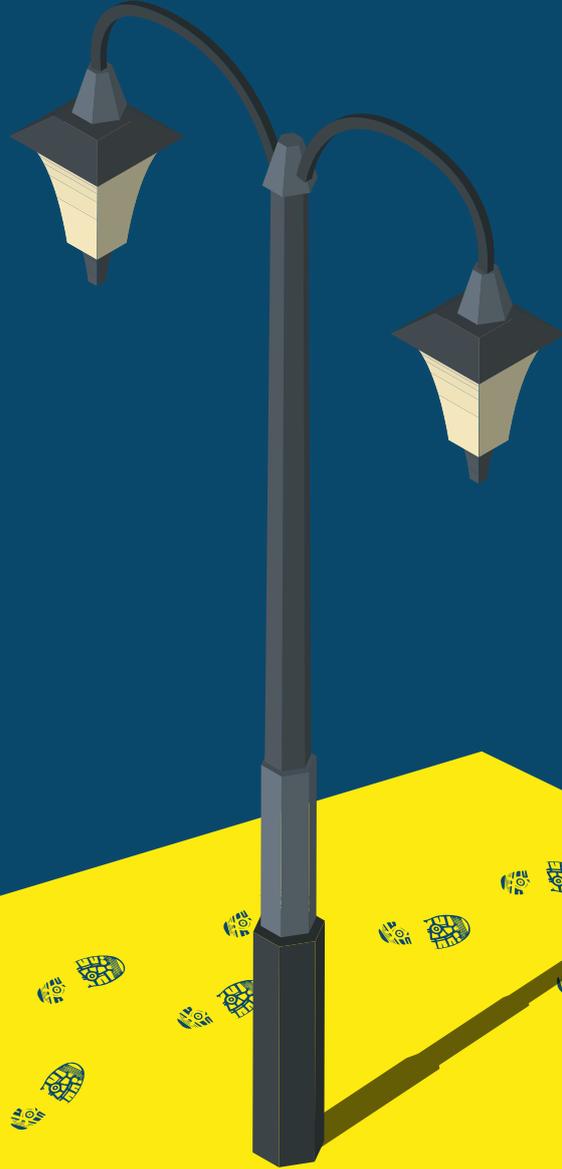
I am seen as Sarah NOT my mental health problems"

*Sarah Holmes
Pathway Expert by Experience*



“I am delighted to support Pathway’s Experts by Experience programme. We know that really listening to the needs and wishes of our patients improves the care we give to that individual, and helps us learn how to make services better for everyone. People who are homeless have often experienced great hardship. It is therefore our moral duty as healthcare professionals to be on their side when things are bad, but also to learn from their harsh experiences, to improve the NHS for us all.”

**Professor Steve Field
Chief Inspector of Primary Care
Care Quality Commission**



“PHE has been pleased to support Pathway’s Experts by Experience work as it has developed over the last four years. This handbook is an excellent example of the kind of support that can help people to speak out about health concerns and healthcare problems. It’s focus on the reciprocal nature of relationships, and the practical personal support that we all need sometimes, echoes what we know more broadly about how our health and our life experience is intertwined.”

**Dr Yvonne Doyle
Regional Director
Public Health England (London)**

A WELCOME FROM THE CHIEF

Welcome to our 'Experts by Experience' (EbE) handbook. We hope that this short guide contains all you need to know about working with us, how we support each other, and what you can expect from your involvement with Pathway.

This is the first edition of this handbook and we would welcome your comments and suggestions on how to make future editions even better.

This handbook has been put together by Stan Burrige, Pathway's EbE project lead, drawing on four years of learning from all the people we have worked with. It includes the ideas and suggestions of the many, many people who have been involved with Pathway's EbE work. I would like to thank them as well all our current EbEs and all the people with 'lived' experience of homelessness who have worked with us over the last four years. They have helped us develop our EbE programme, and been brave enough to share their experiences to help make health services better for others.

Pathway's charitable purpose is to improve healthcare for homeless people and other deeply excluded groups. We do this by working with everyone, from large NHS organisations to individual doctors, nurses, and other healthcare professionals. From the start, Pathway recognised that we could only improve health services for homeless people if we knew what the real health problems and day-to-day healthcare experiences of homeless people were. Everyone agrees that really listening to patients is at the heart of good healthcare. For Pathway, really listening to the experiences of homeless people has been at the heart of our practice ever since we started. Through our EbE programme we have learnt and developed an effective method of supporting people to speak out for themselves.

'To really understand the needs of homeless people, you must first learn from the experts, the people who've lived it.'

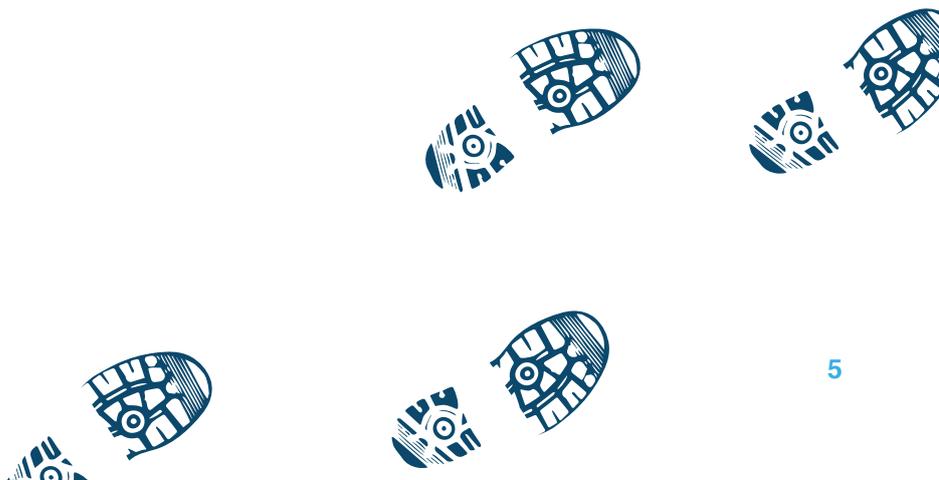
Pathway annual report 2015

I'd also like to thank colleagues from advertising and design agency Frontera who have given a great deal of pro-bono time towards the production of this handbook. For a small charity, it is amazing when you find a partner who understands your world and is willing to offer practical help; and to Dr Yvonne Doyle and Public Health England (London) for supporting this project.

A special thank you to Helen Davies, who has championed this project from the start and helped shaped how we support Pathway's EbEs!

Finally, I wanted to acknowledge and thank Alister Ferguson for his participation in Pathway's EbE programmes over the last three years. He came to two conferences and participated in lots of other activities. Alister died in June 2016, and although he had seen drafts of this document, he never got to see the final version. Our EbE colleagues all agreed that we should dedicate this publication to him, and I am proud to do so.

Alex Bax
Chief Exec. Pathway



ME, YOU AND THE UNIVERSE

Hi, I'm Stan Burridge, Pathway's Expert by Experience (EbE) project lead and it's my job to take you through this handbook and to support you on your journey with us. Most of our EbE projects are about harnessing the voices of people with a real 'lived experience' of homelessness and exclusion and supporting them to speak openly about their experiences. We have a strong belief that by doing this we can influence healthcare providers, commissioners, and the system in general, helping to create a better NHS for all homeless people.

There seems to be only one major difference which separates us all, and that is the unique way we feel our own experiences.

I first started working at Pathway in 2012; my role began by finding out what homeless people were saying about their experiences of healthcare. I carried out surveys and hosted focus groups, presenting the information back to Pathway and the Faculty for Homeless and Inclusion health; sometimes in writing and sometimes just by talking about it. I would talk openly about my own 'lived' journey with those I met; this always made them much more open about theirs.

I would share how my journey began back in the care system. I'd been in and out of children's homes for a long time before finally going into 'care' for good when I was about 8 years old. During my life, I've been a runaway, a rough sleeper, a prisoner, a patient, a hostel resident, and a volunteer; now, I'm a tenant and an employee.

Nearly all the homeless or ex-homeless people I've ever spoken to have had some or all those experiences in their journey, but there's one major difference and that's the unique way we all feel those experiences. My role has developed since then, now it's not just about asking for your stories, it's about looking for ways of bringing you together with other homeless and ex-homeless people, getting you working as a team, and supporting you to speak about your experiences.

The aim of this handbook is to show how we do things in a safe and supported way.

There have been many people who've been involved in Pathway's work over the past few years and they have helped shape what involvement with Pathway looks like. This handbook will explain how we do things, why we do them and just how important your role is with us.

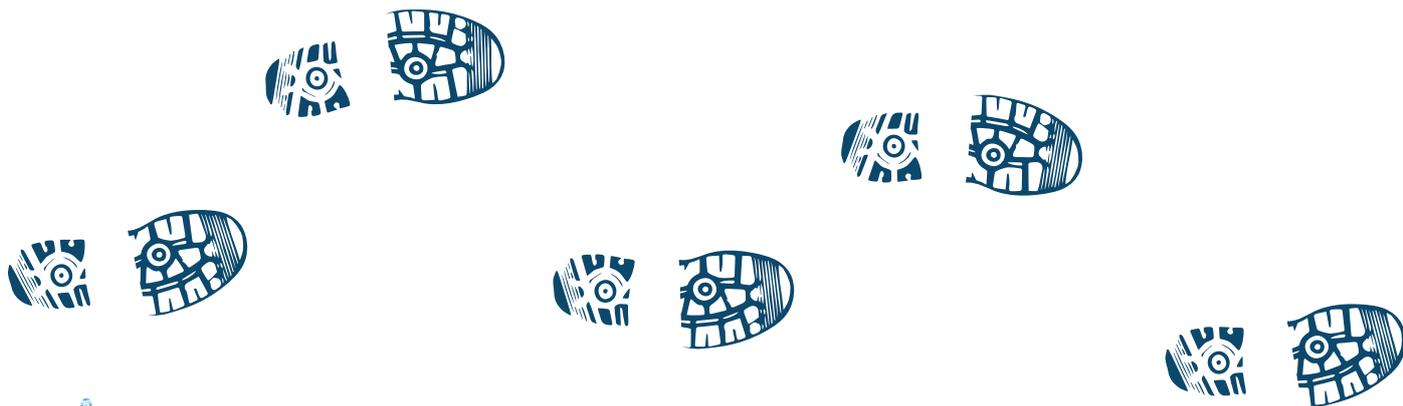
Going through your 'lived' journey has given you lots of experiences. By working with Pathway and sharing them with a wider audience you can be part of a process of learning and teaching. You can help others to understand what it was like being homeless, what worked and what didn't when it came to your own health and recovery and help us to help NHS colleagues and decision makers get it right for others.

It is quite a powerful position to be in.

Having my own 'lived' experience, and now leading this work, makes me determined to ensure that at every step of the way you are reminded just how important you are and how powerful you sharing your experiences can be. It's also my job to do as much as I can to make the time you spend with us both safe and fun.

So, I hope this handbook gives you a clear picture of how we work, the rules we have agreed, and what you are getting yourself into!

I look forward to working with you.



“Working with Pathway as an EbE has given me a safe sounding board to share my experiences of homeless exclusion. For the first time, I feel validated that what I went through can now make a difference to others in the future and that people out there want to listen and make things better.”

***Megan Fitzhenry
Pathway Expert by Experience***



WHY DO WE NEED A HANDBOOK?

I have often been asked “Why do we need a handbook?” Pathway’s EbE work has developed gradually over the last four years and we have learned so much along the way. We think that putting together our learnings and setting out how we do things in this handbook will help us to keep doing the things we get right, and change the things we don’t. This handbook is also about showing Pathway’s commitment to this work.

The main people we have learned from have been our EbE colleagues. They have been involved in putting this handbook together, particularly the ‘We will, you will’ charter.

This handbook is to make sure you know you are part of a supportive structure and that we have thought very clearly about you and your involvement.

As we have developed we have also learned from many partner organisations about how they do things. There is lots of good practice out there and we have tried to draw on some of that when we put this handbook together. As we’ve worked with other organisations they have often asked us how we run our EbE programmes, so that is another reason to pull our approach together in this handbook, so that we can share our learning with other people.

However, the main reason for producing this handbook is for you. We want to make sure that you know that we have thought about what we are doing, how we work together and how we will support you in your involvement with us. This handbook helps to define our relationship with you so that you can be clear about what you are getting involved in, and how we work together. This is only the first edition. We aim to regularly review and update this document so please let us know if there is anything you think is missing, or if we could improve anything that is here.

“Thinking it’s possible to create a one size fits all policy to help homeless people is naive. EbEs see how the entire system works and can provide an invaluable wider perspective, pointing out where there may be conflict and hindrance between the various organisations, providing a bridge to greater cooperation between different service providers”

***Ian Millar
Pathway Expert by Experience***

IT'S ALL ABOUT YOU

The most important thing about your work with Pathway is YOU.

It is **YOUR voice, YOUR experiences** and **YOUR input** that makes all this happen. Almost all of the work you will be doing with us involves talking about your experiences of homelessness and the healthcare you have received, sharing the good, the bad and the ugly. When you are not sharing your own 'lived' experiences you are supporting others to share theirs.

Sharing your life story with others can impact on you in many ways; it can make you feel relieved that you are finally able to talk about a part of your life knowing it will help others; it can bring up feelings that you may have suppressed for a while; it may even mean that you are sharing parts of your life you haven't talked about with anyone else for a while and, in some cases, ever.

This handbook tries to give you a clear picture of how you will be supported while you volunteer with us.

One thing you must always remember is that it's **YOUR life** and **YOUR story, YOU own it**. You have the power to say as much or as little as you feel comfortable with, sometimes only saying just a little or even nothing can be as powerful as saying lots.

Everybody needs to be in a good place and feel supported to begin talking about their own journey, so we will make sure you understand that it's always your choice what you share, when you share it and who you share it with. Whether it is in a large group, a small meeting or at a big conference, you can say as much or as little as you feel you want to.

“There is nothing more powerful than a person who has nothing left to lose, yet still has the courage to stand up and look the world in the eye.”

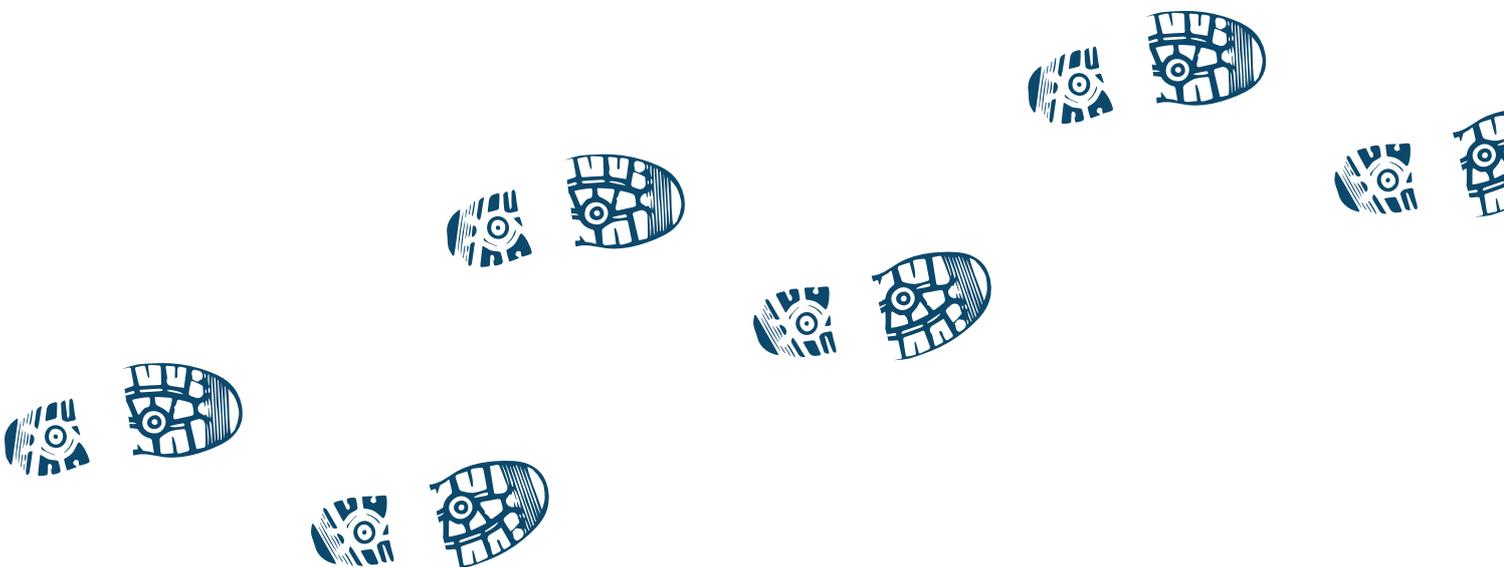
*Dr. Nigel Hewett OBE
Medical Director, Pathway*

As you start to work with Pathway we will put together a short profile of you. This includes some basic information such as your contact details; we will also ask a bit about your life journey (just the basics). We want to keep a note about the things that you're happy for us

all to know. We will use some of those details to keep us aware of your comfort zone. Having this information is really helpful so we know what we need to steer you away from to keep you safe. You may also feel that you want us to know something about you, but don't want to share it openly; Pathway will always keep that sensitive personal information confidential.

Let us know if you change your mind about the things you are happy to share. Remember, just because you have spoken about something once, it doesn't mean you are under any obligation to keep sharing it.

Pathway EbEs are sometimes invited to take part in external events. Before we consider who to ask to take part, we will look at what is on the agenda, and then go through our EbE profiles to see who might be comfortable or knowledgeable about that particular subject. You will always have the final say about what you do or don't get involved in. Speaking at a public event may mean that whatever you have shared is then out in the public domain, so we will make sure you have a chance to think carefully about your involvement at the start.



WHAT IS AN 'EXPERT BY EXPERIENCE'?

Defining the role of a Pathway EbE

This part of the handbook has needed more thinking about than any other. I can start by saying that being an 'Expert by Experience' doesn't mean that you have to be an expert on everything; it is your journey and your experiences that make you the expert on yourself. So we could call it E.B.O.M.O.E (Expert Because Of My Own Experiences). But 'Expert by Experience', or EbE, is easier.

Lots of people in the NHS are also 'Expert by Education', so the phrase 'Expert by Experience' recognises that each of our own perspectives can help others understand.

"The 'Experts by Experience' were really engaging. We could have heard more about how their involvement is impacting on delivery."

Natalie
South Yorkshire
Housing Association

Pathway's Board has agreed the following definition of an EbE:

"Our definition of an EbE is someone who is able to articulate lessons and suggestions from their own 'lived' experience of homelessness and health challenges. Their expertise is based on their own individual experiences, enabling them to speak with authenticity. EbEs can also be in a unique position to connect to others with similar experiences, bringing a wider range of 'lived' experience views to partnership working."

Our ability to listen to individual and collective EbE voices gives greater power to Pathway and the Faculty for Homeless and Inclusion Health to identify failings within healthcare provision for homeless and excluded groups, as well as suggesting areas where there is room for improvement or to celebrate good practice.

"The 'Experts by Experience' stories and bravery provide me with the greatest motivation to devote my career to working in this field."

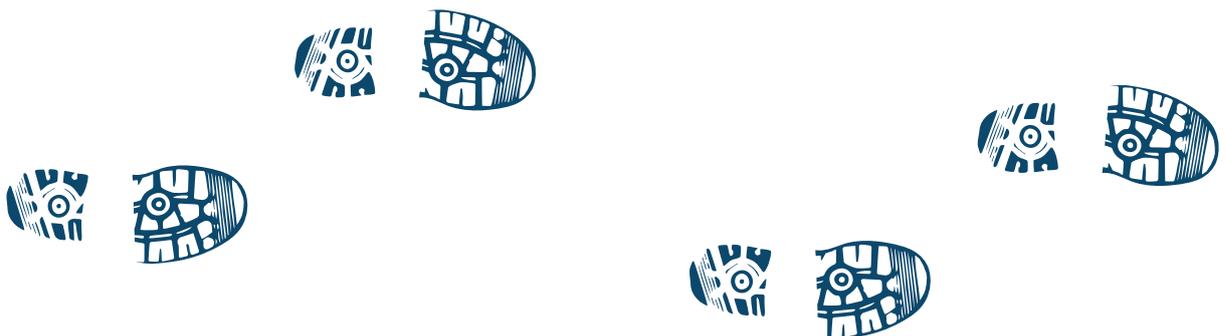
Medical student

The role of an EbE is very different from 'normal' volunteering. The core skills that are needed for this role are:

1. The ability to talk about your 'lived' experience in an open and honest way (the things you are comfortable with).
2. The ability to support others when they talk about themselves and their experiences.
3. You must be able to get on with others in a friendly way. This is an excellent skill to have and one you will be using more than any other. Very often Pathway EbEs work together as a group, but don't worry if you haven't ever done any formal teamwork. It's one of the things that our past EbEs talk about as the one of the best bits of getting involved with us.
4. Finally, you have an interest in helping to improve healthcare, and what the NHS does in particular, for all homeless and excluded people.

These are the four things we think an EbE needs to have as a minimum.

Being a Pathway EbE is also a learning curve, and learning is a two-way thing. As you begin to teach others by sharing your views and experiences, you will also learn about them, the systems they work in, and how healthcare works across the board – learning and teaching in equal measures.



“I enjoy volunteering as an Expert by Experience for Pathway. I have done lots of things I enjoy. I feel comfortable, everybody treats me well and I always feel as though I have support if I need it.”

*Viv Askeland
Pathway Expert by Experience*



WHERE WE SHARE

To give you an idea of the type of things we have done, here are some examples:

- We've conducted simple surveys capturing the voices of people with 'lived' experience of homelessness, organised focus groups for NHS partners and other agencies and produced reports that shared those views.
- We supported and funded 14 ex-homeless people through a dentistry programme, getting their teeth fixed and looking at ways to improve oral health for homeless people and influence how services are commissioned.
- We've developed shared learning exercises on homeless health for year 1 & 2 medical students for several universities.
- We've designed and delivered EbE presentations for doctors and other medical practitioners that counted towards their professional training and development.
- We've taken the EbE perspective to Pathway hospital teams in London, and have worked with other medical teams who base their services on the Pathway model in other parts of the UK.
- We support and train EbEs to take part in the Faculty's annual International Homeless and Inclusion Health conference. For our conferences, we offer extra training so everyone feels confident enough to fully participate as an expert.
- Pathway's EbEs have also worked with NHS hospital trusts, GP practices, NHS England, the Care Quality Commission, Public Health England, and many others.

OUR MINIMUM COMMITMENT TO YOU

Pathway is a small charity so we have limited resources. Our EbE work is sometimes restricted by money, time and sometimes the requirements of the organisation we are working with.

There are four things Pathway will do for you if you join one of our EbE programmes:

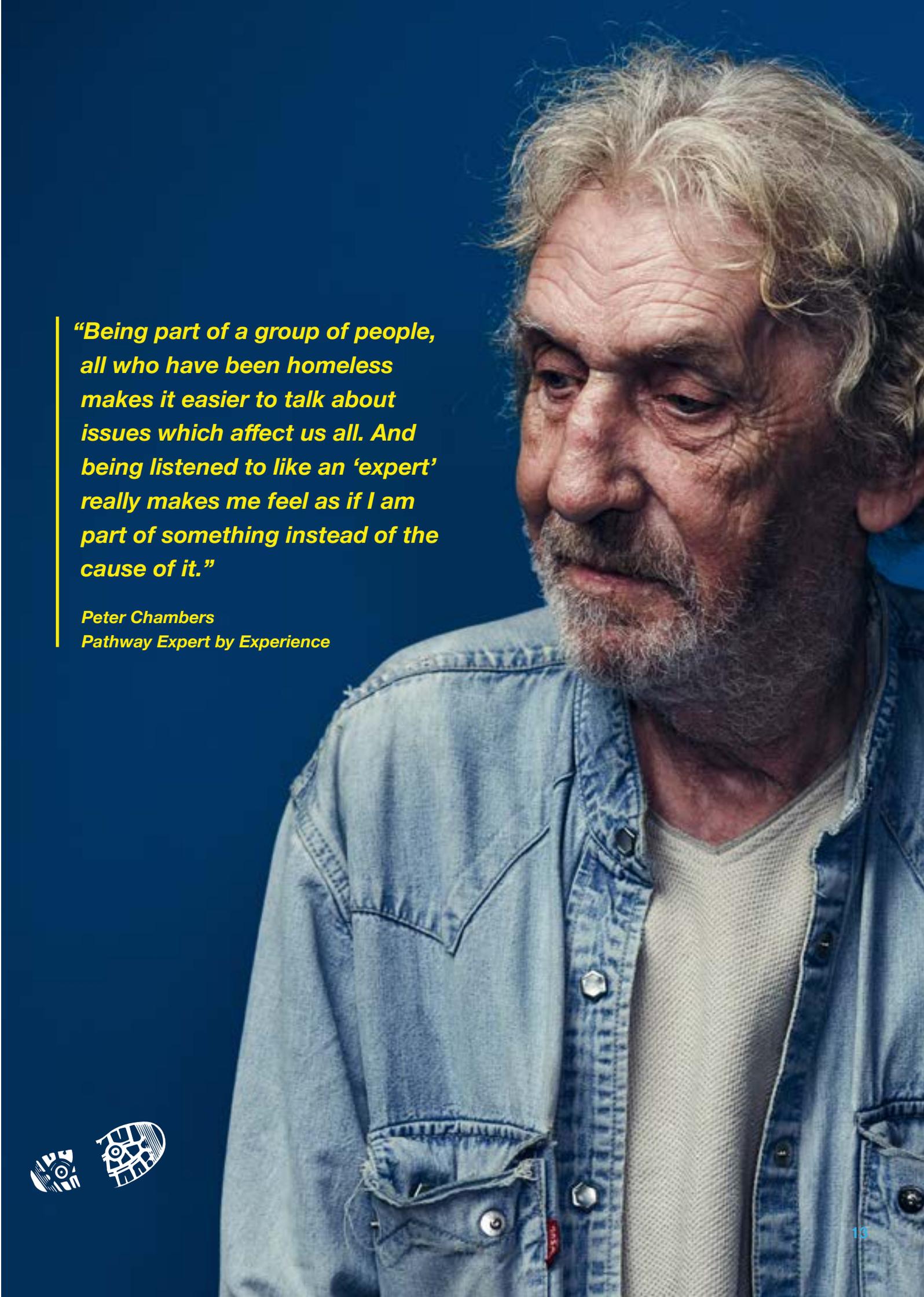
1. We'll register you as a member of the Faculty for Homeless and Inclusion Health. Membership is open to nurses, doctors, medical professionals, social workers, public health experts, health advocates, support workers, commissioners, researchers, and people with a 'lived' experience of exclusion. Being a member of the Faculty means that you will get regular email updates. There are also meetings in London every 3–6 months and across the country at different times. (Let us know if you want to attend a Faculty meeting, sometimes we can offer help with travel expenses to get you get there).
2. We will enter your details on our EbE database so we can keep you up-to-date with our work and let you know about any opportunities you might want to be involved in. We will only keep you on that database for as long as you want us to, please let us know if you want to be removed.
3. We will keep reviewing the way we work, learning from you and others and updating this handbook from time to time. Please let us know if you think we are missing something or if you feel that changing some of the ways we do things would be better, and make it more inclusive.
4. We will always provide support for you to participate in any event. We will make that support individual to your needs and we will actively work with external agencies to make sure they offer the same level of support when you are taking part in one of their events.

"Nothing makes me feel more accepted or respected than when I am being included in the big picture. I have volunteered for a large number of organisation over the past 10 years but I am always drawn back to the ones that treat my effort and experience with the credit it deserves.

Feeling included gives me hope for the future."

*Joseph Ellis
Pathway Expert by Experience*





“Being part of a group of people, all who have been homeless makes it easier to talk about issues which affect us all. And being listened to like an ‘expert’ really makes me feel as if I am part of something instead of the cause of it.”

***Peter Chambers
Pathway Expert by Experience***



We Will/You Will

Our working relationships & Managing expectations

Over the last 4 years, Pathway's EbEs have developed this simple charter that sets out some basic rules for the way we should work together, our expectations of you, and what you can expect from us.

"We are not interested in involvement for its own sake; for involvement to be meaningful, it must make a difference. It should lead to the improvement of services and the mental health and wellbeing of service users and carers. Becoming involved can also have a positive impact on the people who are involved (for example, by giving them the opportunity for increased skills and confidence). The purpose of involvement should always remain at the centre of any attempt to assess impact."

Alison Faulkner
National Involvement Standards
NSUN





We will / You will

VALUE EACH PERSON'S CONTRIBUTIONS AND TIME

WE WILL always try to match volunteering opportunities to your interests and skills, dividing them equally so everyone can benefit from a range of experiences while volunteering with us.

YOU WILL tell us about your interests and how much time you have available for EbE roles; this information helps us to make the best use of your time, and helps you to get the best from volunteering with us.

WE WILL provide you with clear instructions and explain the support provided so you can complete each role you undertake. We will always try to provide you with enough preparation time and training so that you can carry out the task to the best of your ability.

YOU WILL discuss with us any concerns you have. If you are unsure about something, **YOU MUST** let us know. Also, tell us about any additional support or training needs you have that will help you more.

WE WILL do our best to keep to an agreed start and finish time for meetings, and make sure that everyone has the chance to contribute their experiences or ideas within a group. If an event is cancelled, we will let you know as soon as possible.

YOU WILL keep us informed of when you are available. Once you have agreed a time and date, please organise your day around that commitment. If you cannot make the agreed time/date, let us know straight away so that we can fill that space with another volunteer. Always make sure that you arrive in good time for the event.

WE WILL always encourage input from everyone, and will use different techniques to make sure that everyone has the chance to speak. We will encourage you to speak about your experiences and contribute to any event you are taking part in; we will also support you to remain safe.

YOU WILL remember that when you take part in any meeting or discussion session you only have to say as much or as little as you feel comfortable with. **YOU WILL** be expected to actively support others to be involved– it is important that we all look after each other.

MAKE IT EASY TO PARTICIPATE

WE WILL provide you with clear information and discuss any practical arrangements needed for you to take part in an event, including: location, timings and who to contact in case of questions at the event.

YOU WILL let us know straight away if you have any questions or concerns about an event or if you need any additional support or special arrangements such as access or dietary requirements.

WE WILL provide you with all the necessary background information ahead of time so that you can be well-prepared for meeting or events (agendas, documents, details of other participants.)

YOU WILL allow yourself sufficient time to read through any background papers you are given and take the time to ask any questions you have before the event.

WE WILL provide you with details of the venue and assist you with travel arrangements.

YOU WILL plan your route and arrive on time. If you need help finding the best route or have any other needs, please let us know well in advance.

WE WILL always cover your travel costs and any other agreed expenses, repaying you on the day.

YOU WILL provide the correct receipts for your travel. You must arrive in plenty of time if your train has been pre-booked for a specific time. You must fill in the correct information on the form provided, if you have difficulty filling in that form, let us know and we will fill it in with you. If you fail to make an event, and have not told us you are unable to attend, you may be asked to repay the cost of the ticket if it has already been purchased.

WE WILL make sure that everyone has a copy of this booklet and as you to agree to follow these rules.

YOU WILL agree to stick to the basic rules of involvement and if in any doubt regarding the contents please ask.

LOOK AFTER YOURSELF & EACH OTHER

WE WILL always look at any potential health-related risks there are to your involvement and we will discuss these with you.

YOU WILL let us know if there are triggers or risks to your health and well-being, and help us to understand what works best to help you manage those risks.

WE WILL encourage you to take care of your own physical and mental well-being and where possible, we will signpost sources of advice or support to get help with this.

YOU WILL take care of your own health and well-being, make use of any advice and support [that is available and encourage others in the group to take care of themselves too.

WE WILL be very clear about what we can and cannot assist you with in relation to your health.

YOU WILL always put your own health first. You must keep us informed about anything that may impact on your ability to volunteer.

WE WILL always take into account any health-related needs you have informed us of when planning your involvement.

YOU WILL let know of any healthcare needs we should be aware of or if there any additional support needs you have that can affect your involvement with Pathway.

“So brave and really great to hear about the ‘Experts by Experience’ progression and involvement.”

*Camilla
KCM NHS Trust*





RESPECT EACH OTHER

WE WILL always try to involve EbEs from diverse communities and check whether they have any cultural or other requirements to help them participate.

YOU WILL let us know if you have any specific or practical requirements to do with equality and help us to monitor our equality policy effectively.

WE WILL always create a welcoming environment for people to attend meetings and events and will make arrangements that always take into account any additional needs they may have.

YOU WILL always be welcoming to others who bring different views and ways of working to the group, and take the opportunity to learn about and celebrate each other's differences.

TAKE CARE WITH CONFIDENTIAL INFORMATION

WE WILL be very clear when we are asking for information about you. We will explain what it is for and what we are going to do with it. We will never expect you to share any more than you are comfortable with, and this is regardless of whether it is only with us, or at an external event.

YOU WILL take care with your own story and any personal information you share; remember it is your story, you own it. You can ask for advice if you have any worries. Never share any more than you're comfortable with. If you feel uncomfortable at any stage, stop and let us know.

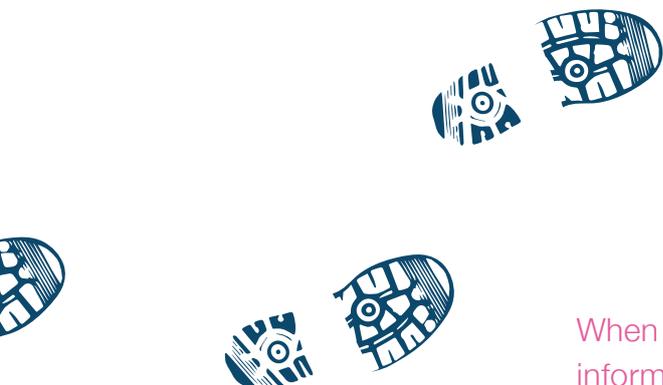
WE WILL only keep relevant personal details about you. We store them securely and do not share them without getting your informed consent first. The only time when we won't seek your permission is if there is a risk to you or others if we didn't share that information.

YOU WILL treat any information that has been shared by others as importantly as you would your own. You must never pass on anything you hear to anyone else unless you've checked it's OK to do so. You must not provide information that identifies others. You must help us to help keep you safe by telling us anything that you feel we may need to know.

WE WILL always re-check any information we use about you to confirm that it is still accurate and that you are still happy for it to be shared. **WE WILL** also talk to you about who it is going to be shared with and what it is going to be used for.

YOU WILL always be asked to make a decision about whether your information is shared and who with. Once you have given your permission, you need to let us know if you change your mind. Please remember, if you agree to share things about yourself in public, then we will not be able to undo that, we will talk to you about this.

When you have finished volunteering with us we destroy all information about you that is no longer needed. Printed or electronic material which you may have helped to create may remain in circulation and on the internet. Please talk to us if you are unclear about anything to do with any information we hold about you.



RECRUITMENT AND SELECTION

There are a number of ways that people become involved with Pathway EbE work. It is more than likely that you will have come to us through one of the more popular ones:

1. Word of mouth from another EbE.
2. When working with a partner project or agency.
3. You have been suggested to us by another organisation you are involved with.

Being part of a group of people who are all pulling in the same direction can give you a sense of purpose and a sense of ownership over the work wthat you are doing.

It doesn't matter how you get involved with us, what matters is that we share common aims, which are the willingness to have your voice heard and the desire to make a difference for others. If between us we decide that you want to volunteer your time with us then we will want to get to know you a bit better.

- We will discuss how much time you can commit to any specific project and whether it is sufficient.
- We may need to find out how much experience you have about a specific subject. It could be that you won't be suitable for the project we are working on this week, but next week you are the ideal person.
- Before we ask you to get involved in any project we will always talk to you about where you are at in your life to make sure that you are in a safe place to be able to volunteer. (This is important because we have to make sure that working with us, and talking about sensitive issues will not leave you feeling more vulnerable.)
- We will help you to build positive relationships with other members of the Pathway EbE group. Team work plays a large part of the work we do and we have to make sure that all the pieces fit together.
- We will always try and match the right person to the right opportunity so we will make sure you get an equal chance to explore the different opportunities there are to volunteering with Pathway.
- We will keep a record of the different things you do with us to make sure we are being fair.
- We are always open about the decisions we make and we will be honest with you about our reasons to select one person over another.
- We ask all our EbEs to keep us informed about where they are at in their lives to help us make the right decisions for them.
- Please let us know about any skills that you possess that you think might contribute to our work, or help other members of the team. Pathway EbEs develop as much of a role as a teacher as a pupil, by teaching and learning together.



TEAM BUILDING

- The first and most basic part of your involvement with Pathway as an EbE is getting you to work and feel part of a team. A team of individuals who are all pulling in the same direction gives a real sense of purpose and ownership over the work we do together.
- We always try to arrange things so that we can have lunch together as a team and try to organise it so that this is away from the office or the working environment. We are always looking for other things we can do together as a group so if you have any suggestions, let me or the group know.

OH DEAR, BAD NEWS

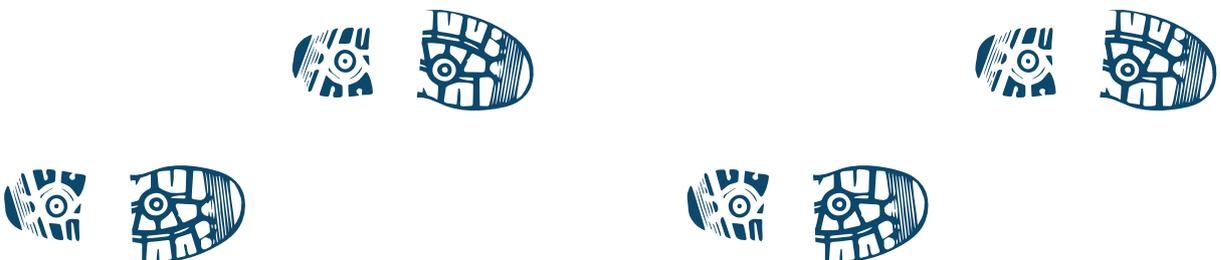
Being homeless is bad for people's health so it's quite common for Pathway EbEs to have their own health problems. Pathway, as an organisation, works towards improving the NHS services for homeless people and other excluded groups, but Pathway is not a healthcare provider so we are unable to provide you with healthcare or personal health support.

We are a small charity and have a limited capacity to offer lots of support. That said, we will try to advise if you are experiencing difficulties, and other members of our EbE groups will often support each other too. If you become ill while you are volunteering with us we will advise you to go to your own GP; if it's urgent we will help you get there, if you need that support.

We might be able to find you some help or support elsewhere or signpost you to an open access GP service or a walk-in clinic. If you are not registered with a GP we may be able to help you to get registered. The key message is: if you are struggling with something please tell us, and we will help if we can.

Pathway cannot get involved in matters regarding the treatment you get from your own GP, your prescriptions, the medication or any other issue that is between you and your healthcare worker. However, while you're with us we can support you in other ways: you can use the office telephone to make appointments, and we can help you to understand your rights to NHS services.

Pathway works to improve the NHS for homeless people and other excluded groups but we are unable to provide you directly with healthcare or health support.



All the important stuff

TRAVEL EXPENSES POLICY

Generally, you will be asked to pay for your travel in advance and claim it back on the day. If this proves to be difficult then we will help plan your travel and pay for it in advance. We understand that it may cause you difficulty if you have to wait for refunds for travel expenses you have paid out, so it is our policy ALWAYS to refund your travel expenses in cash on production of the correct receipt. If you have any special travel needs please talk to us in advance so that we can try to make arrangements that work for you.

The agreed rates of reimbursement for London are a travel card for the correct zones or an Oyster card top-up to a maximum of the daily cap rate.

Receipts must be dated same day or previous day unless otherwise agreed.

Taxi fares WILL NOT be refunded unless pre-arranged. If we have agreed that you will travel by taxi, this will be booked and paid for in advance by the Pathway office (please make sure you are at the agreed meeting point in this case).

Travel involving National Rail journeys will be refunded on the basis of a second class return journey to and from an agreed starting point to the venue. Pathway will normally buy National Rail tickets in advance and arrange for them to be delivered to your home/contact address by first class mail (signed for) or collected from your local station. Where this is not possible, a cash reimbursement will be arranged upon presentation of a valid receipt for the journey.

OVERNIGHT STAYS AND MEALS POLICY

There may be occasions where an overnight stay is needed for you to be able to participate in an event, for example our annual conference. On these occasions, Pathway will be responsible for arranging suitable overnight accommodation for you. Travel will also be arranged on your behalf.

If we agree that an overnight stay is necessary then this will be booked and paid for in advance. It will include bed and breakfast, and a separate arrangement will be made for your evening meal.

Although the full cost of accommodation and meals will be met by Pathway, the use of room service and mini-bar or additional services will be your responsibility, and Pathway accepts no liability for this.

Any additional costs relating to an overnight stay must be agreed prior to the event, and if agreed Pathway will meet these costs. Pathway will not reimburse any expenses that have not been discussed and agreed in advance.



Keeping you safe with policies and forms

LUNCHES AND REFRESHMENTS POLICY

Lunches

Lunch will be provided by Pathway for internal EbE events lasting more than three hours and covering some or all of the time within the normal lunchtime period (12:00–14:00). Sharing a meal together is a good way to get to know each other and helps build the team feeling, so you will be expected to join in with lunch as part of your day.

We try to have lunch away from the building, and as a group you will decide where to go. A maximum budget of £10 per person per day is available for lunch. (This will be reviewed annually and rise in line with costs.)

Sometimes we may ask you to attend another organisation's event on our behalf. Obviously we cannot control their processes or rules but we will find out this information before you attend. If we are informed that lunch will not be provided, or they are unable to meet your dietary requirements, then we will provide you with a lunch budget of £10. You must bring or send us the receipt for your meal.

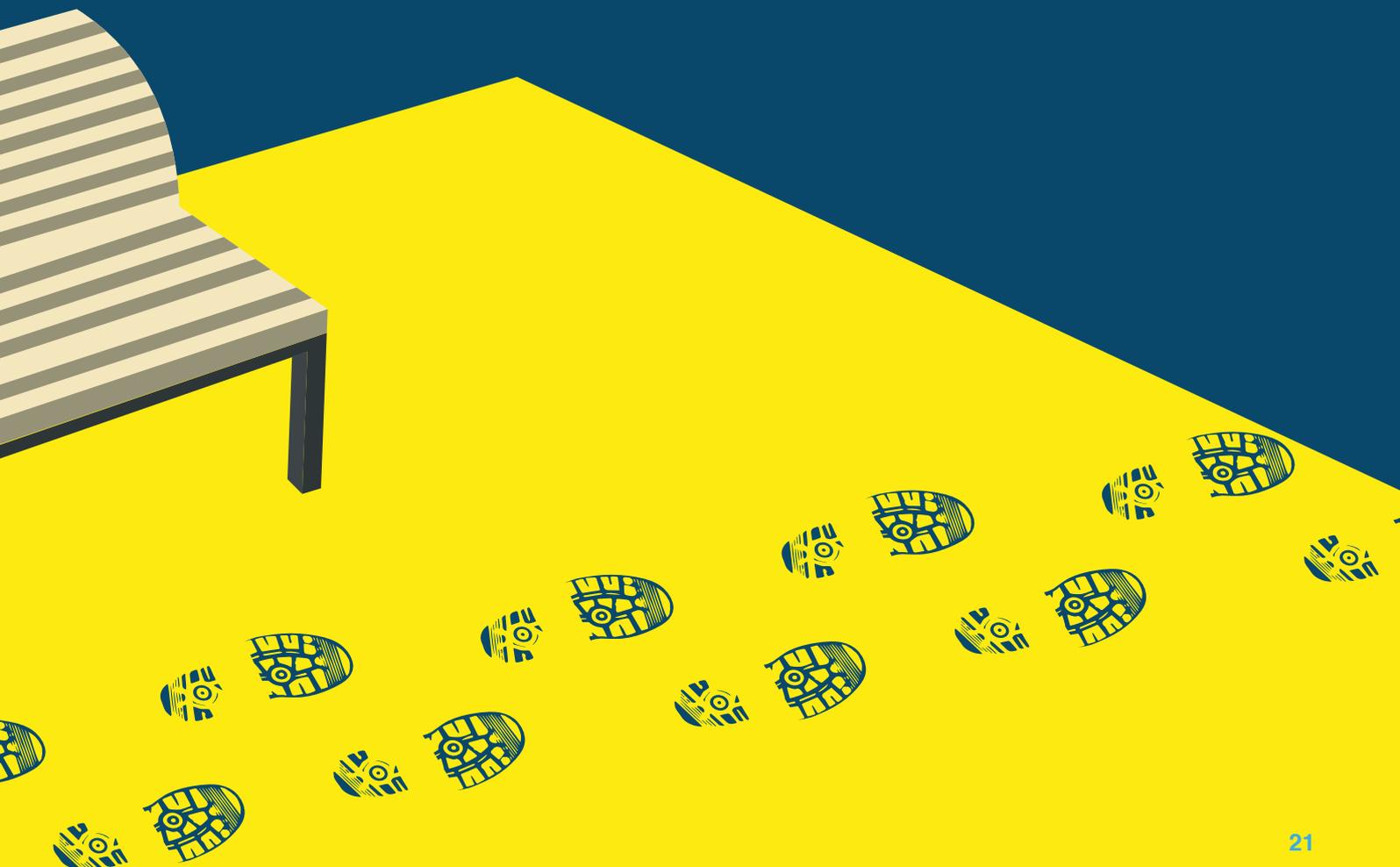
For both internal and external events where a meal is provided please make sure to tell us if you have any food allergies or special dietary needs.

Refreshments

During most of our work tea and coffee will be provided by Pathway at regular intervals. Drinking water is constantly available, and soft drinks can be supplied if requested as a replacement for tea or coffee.

Please note, the consumption of alcohol during group lunches is not allowed, to protect members of the group. The café or restaurant owner/manager will be asked in advance not to accept any order for alcoholic drinks.

(See alcohol/drugs policy)



CONFIDENTIALITY AND DATA PROTECTION

In your work with Pathway you will often share aspects of your personal life and healthcare experiences; this will be with others in the group as well as with NHS professionals. This is a very powerful way to show people how services need to change, but it also means that you can be sharing sensitive information about yourself.

Pathway has to be careful with how we keep and store this information. Very often when we use people's stories to help make a point we will change the names and other key facts to disguise their identity. As with everything else, we will talk to you about this up-front. Always remember that it is your story and you need to think about how and when you want to share any part of it.

At the start of your relationship with us we will discuss what we do with any data or information we record about you. We will explain how we use it, store it and dispose of it. As previously explained, Pathway will keep a basic file that contains information about you, to keep you safe and to help us make sure that you are able to get the best from your volunteering. We have to follow various laws to keep certain information, but we do this in the least intrusive way we can, and we NEVER share any sensitive information with an outside agency unless we are legally required to do so, or without your up-front clear, informed consent. You can access the notes we keep about you whenever you want, and you can have a personal copy of anything we have written down about you.

Any information that we keep about you is covered by the Data Protection Act. The full Act is many dozens of pages long, so here a few key points relevant to Pathway's EbE work:

- We will only keep data about you for the purposes for which it was first obtained. Sometimes we may ask you if we can use this information for other reports and presentations in the future. If you give your consent, we will inform you each time we use it and confirm with you that it is still ok. Very often we use stories from people's lives to make a point so where possible we will look at ways of writing these stories which do not reveal the identity of the person we are referring to.
- Each time we ask you to take part in a new project with a new partner organisation; we will discuss with you what kind of things you might want to share. If anything is going to be recorded or written down, we will make sure you have given your consent.
- All data that we do keep is kept for a limited period of time after the particular project has been completed. Core personal data will not be kept for longer than six years from the end of the project.
- We will always try to ensure that the data or information we hold is accurate. If you think that we hold information about you that is no longer accurate, is out of date or you want to withdraw your consent for us to use it, please tell us. We will destroy the information at the first opportunity.
- Material that has been published or online is very hard to withdraw. We will always get your consent before we use any photos of you or your story.
- All data we hold will be kept safe and secure.
- No information about you will be transferred to another organisation without your express permission.

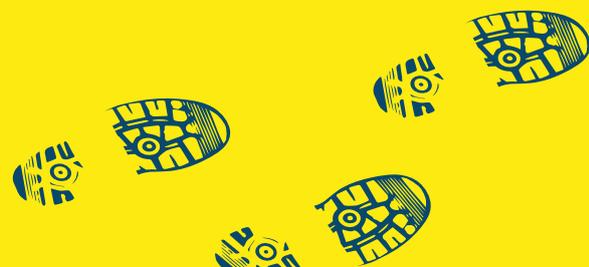
COMPLAINTS POLICY

Pathway always tries to create a safe, welcoming and enjoyable experience, but if you feel that something has gone wrong or could have been done better, please tell us so we can try and fix it for the next time. If you are not happy with our response you should in the first instance raise your complaint with Pathway's EbE project lead.

If you feel the response you are given has not been satisfactory then please ask for a copy of our complaints policy, which tells you how you can raise an issue more formally.

LONE WORKING POLICY

As a Pathway EbE you will not generally be asked to do anything where you are left alone with service users in other projects or on the street. If, while volunteering with us, we ask you to work with other current service users we will ensure that either a core Pathway employee, or a fully briefed responsible staff member from our host organisation (for example, a NHS Trust), is always there with you. As mentioned elsewhere, if you feel uncomfortable with anything we ask you to do, please talk to us, and you can always just say 'No'.



INCENTIVES/ REWARDS

We believe that the time you spend volunteering with us is important and it has value. In order to recognise the value we place on your input we will usually try to offer you a reward for your time. Rewards may be in the form of a gift voucher or a paid leisure activity. It is our way of saying thank you for your time and commitment.

Where we can, we will also try to help with other practical things, for example giving you a reference for job or a volunteering opportunity with another organisation. The incentives and rewards we offer do vary from project to project and is dependent on what budget is available. When appropriate we ask our funders to support reward schemes for EbE participation so when we are applying for funding and grants, the application will always include a funding bid to cover all of the costs relating to your volunteering. Pathway also encourages all external agencies we work with to offer similar incentives, but this cannot be guaranteed. In cases where you participate in EbE work for an external agency and they have not agreed to give you a reward Pathway is not under any obligation to offer you one instead.

We will, of course, always discuss the terms of your involvement in advance so you will know what to expect up front including whether there will be an incentive, and then you will be able to decide whether you still wish to take part.

Any reward you receive is a token of thanks and is not a payment for work you have carried out, either for Pathway or a partner agency.

DRUG, (IL)LEGAL HIGHS AND ALCOHOL POLICY

Pathway is keen to work with people with current experiences of drug and alcohol problems. However, the use of illegal drugs (including legal/ (now) illegal highs) or drinking alcohol while you are with Pathway or attending an event on our behalf is not permitted.

Prescription medication is obviously allowed, but you are responsible for your own medication. Please remember that prescription medication is for your use only, and sharing your medication is not permitted.

Some Pathway EbEs are in recovery from alcohol or drugs, and we feel that it is our duty to these colleagues to put in place rules that support their recovery.

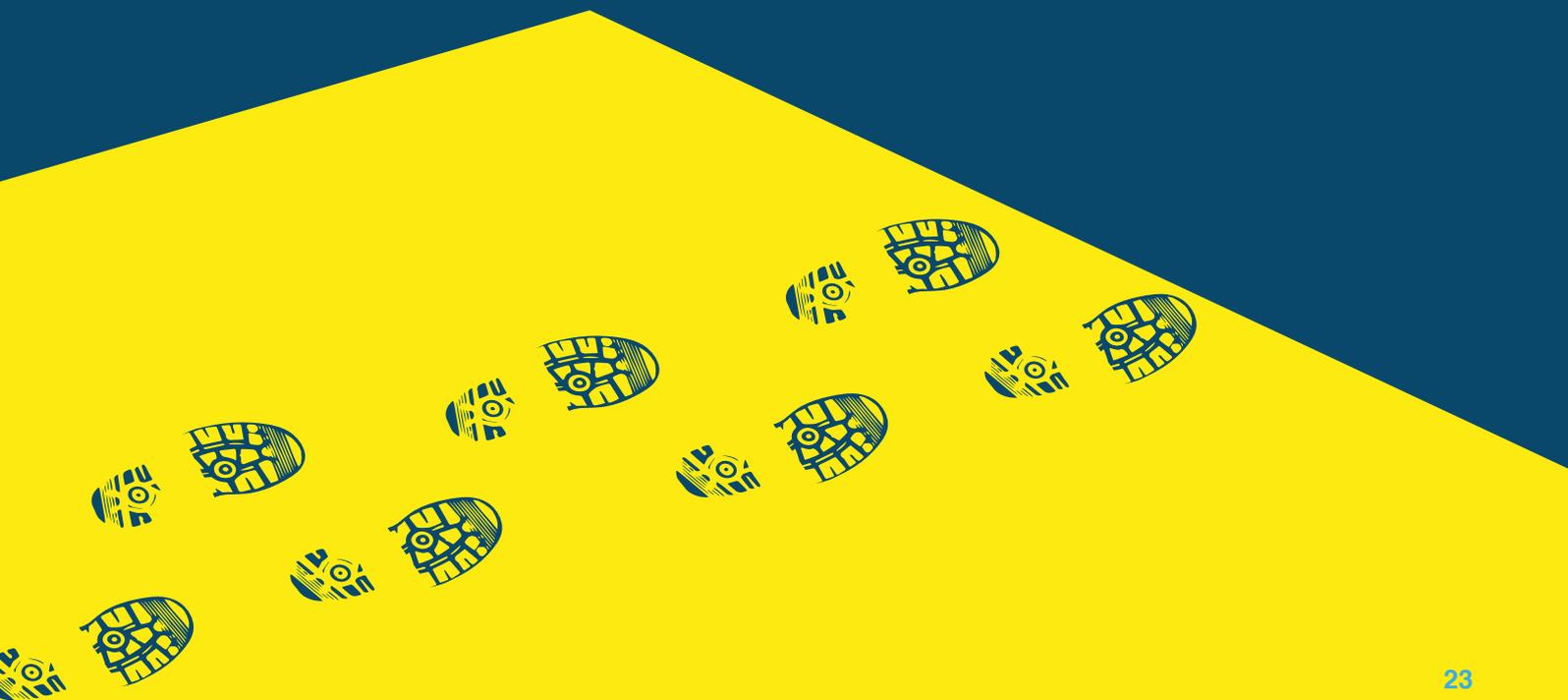
If you bring alcohol, drugs or prescription medication that is not your own then you will be asked to leave and will not be allowed to return to Pathway until the matter has been discussed and resolved with the EbE project lead and the rest of the group.

Please tell us in advance about any alcohol or drug issues you have so that we can support you and help you to avoid any risky or difficult situations.

There are occasions after an event or meeting where some people will go to the local pub. Pathway does not want you to feel that you can't join in, but ultimately, it's your responsibility to keep yourself safe. Please tell us in advance if you are uncomfortable with situations where alcohol is available. A senior volunteer or Pathway staff member is always happy to remain alcohol-free to support you or anyone else who feels that they need that added support.

Please note: Due to an increase in the use of so-called legal highs, this policy now includes the full range of other substances that impair thoughts and actions, including legal highs and solvent-based products.

*Being a Pathway EbE is
a wholly voluntary activity*



ACKNOWLEDGEMENTS WE WOULD LIKE TO THANK:

- Dr. Yvonne Doyle, London Regional Director for Public Health England, for supporting the publication of this handbook.
- Professor Steve Field, Chief Inspector of General Practice, for his kind words and endorsement of our EbE work.
- Pathway is extremely grateful to all of our fantastic Experts by Experience, without their amazing honesty this handbook would never have been possible.
- We want to thank the Faculty of Homeless and Inclusion Health, and partner agencies, for all of the support they have offered during this process,
- A special thank you must go to Helen Davies; without her unwavering support, encouragement and guidance this would never have got off the ground.
- Thank you to Jan-Bakker and purplemattfish for allowing their images to be used, and Charlie Clift for giving us permission to use his portrait photographs of our EbEs.
- And lastly, a huge thank you to Sarah, Katherine, Craig and the whole team at Frontera London. www.fronterlondon.com for the design of this handbook. Pathway acknowledges the fantastic work they have done to help us achieve such an excellent end product.

Pathway works to improve healthcare for homeless people. Pathway developed a simple model of enhanced care co-ordination for homeless patients in hospital, now adopted by eleven NHS Trusts and helping over 3,000 patients every year.

Pathway works more generally to improve the care of homeless patients, carrying out research, exploring and testing new care models and working with and lobbying NHS commissioners. Pathway's Experts by Experience Programme (EbE) supports people with lived experience to participate in our wider body of work.

The charity created and hosts the Faculty for Homeless and Inclusion Health, a network of over 800 healthcare professionals with people with lived experience of exclusion, including vulnerable migrants, people who are homeless, from gypsy and traveller communities or who sell sex.

Healthcare for homeless people

Pathway

5th Floor East
250 Euston Road
London NW1 2PG

info@pathway.org.uk
www.pathway.org.uk

0203 447 2420
Charity Reg: 1138741

