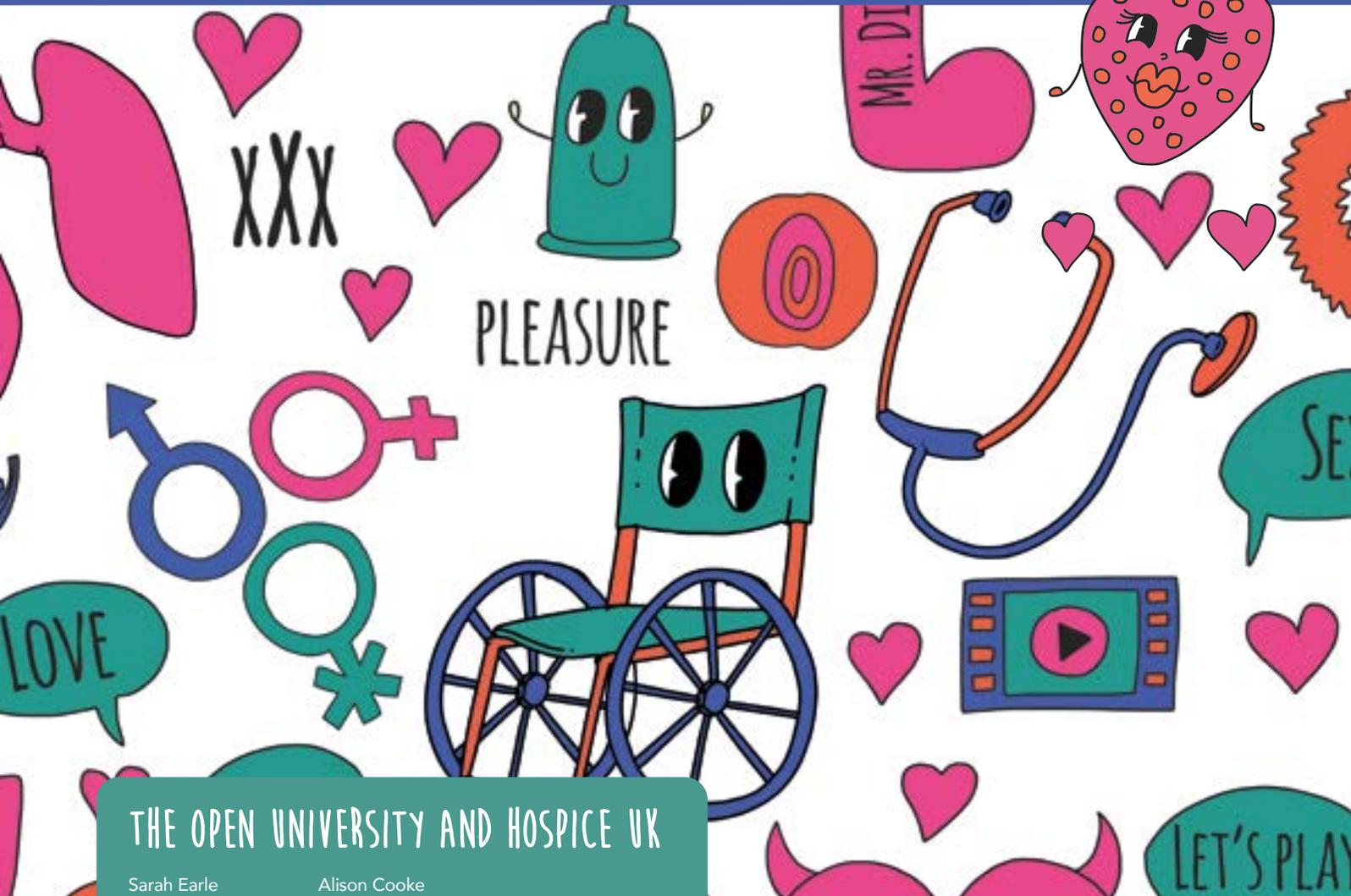


# TALKING ABOUT... SEX AND RELATIONSHIPS:

Young people speak out

FINAL PROJECT REPORT



THE OPEN UNIVERSITY AND HOSPICE UK

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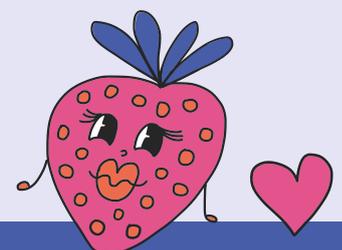
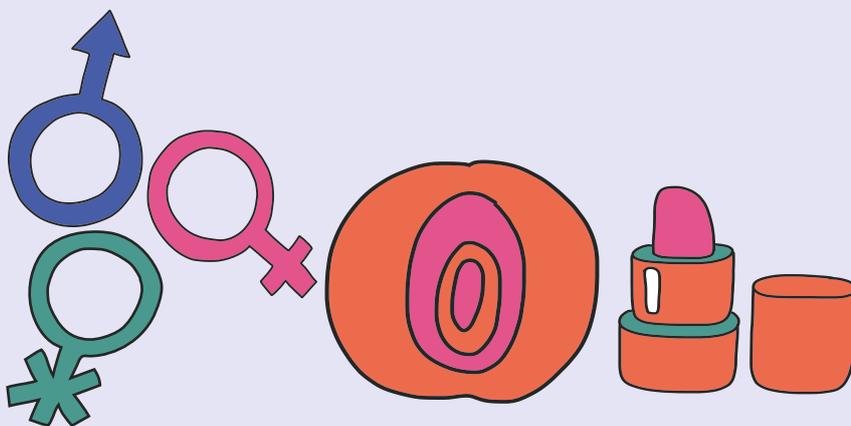
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A project funded by the Improving Transitions  
for Young People Fund, Together for Short Lives



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# 1. INTRODUCTION TO THE PROJECT

The **Talking about... sex and relationships: Young people speak out** project was designed to develop a range of Open Educational Resources (OERs) to facilitate young people (age 14-25) with life-limiting or life-threatening conditions (LLTCs) to have conversations about sex, intimacy and relationships with their family, carers or professional support staff. The project was also designed to equip practitioners to provide better support to young people on this topic through knowledge, resources and a better understanding of the views and experiences of young people themselves.

In partnership with Hospice UK, the project was led by a group of young people known as *AdversiTeam*, who form part of The Open University's Sexuality Alliance. Hospice UK recognise the urgent need to drive improvements in the care and experiences of young people and adults with LLTCs, with a particular focus on improving the transition process. This project is funded by *Together for Short Lives* and is part of its 'Improving Transition for Young people Fund'.

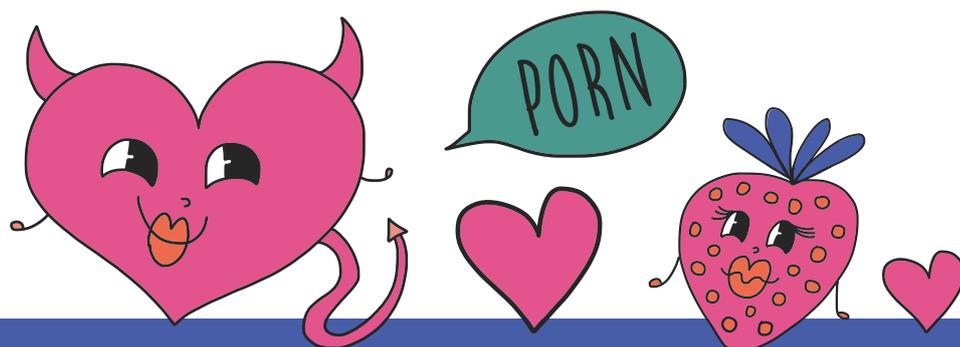
The project began on 1st November 2018 and was organised into two main phases. In Phase 1, we developed, tested and disseminated a series of mixed-media OER on topics that young people identified as important to them. The resources were designed to provide accessible, fun knowledge and information, as well as to develop skills to enable young people to speak with key stakeholders about these issues. The OERs were produced by, and featured, members of *AdversiTeam*. In Phase 2, we developed a short booklet to accompany the online resources. The booklet has been written and designed with the support of *AdversiTeam* to ensure that it focuses on issues that concern young people. The project ended on 31st October 2020.

## 2. ADVERSITEAM: YOUNG PEOPLE SPEAKING OUT

*AdversiTeam* are a diverse group of young people whose lives are likely to be shortened. The group is led by Lucy Watts and is located within a closed Facebook group, where the young people share ideas, thoughts and wishes, comment on and contribute to work, network and collaborate, but also offer support to one another. It has approximately 18 members although membership changes over time. Experience of sex, intimacy and relationships varies enormously within the group and the group is diverse in relation to age, transition, gender identity, sexual orientation, ethnicity and neurodiversity.

Young people have been involved in the development, design and delivery of this project from the outset. The proposal for the project was developed during a workshop held in April 2018 at Chicheley Hall, Milton Keynes which was organised by the Open University Sexuality Alliance; young people, their carers and family members all contributed to discussion and debate. In particular, we talked about the importance of young people being involved in, and leading, the project, rather than the project being led by others. The idea of setting up *AdversiTeam* developed from this discussion.

In the following weeks and months, drafts of the proposal were shared with *AdversiTeam* members who provided critical feedback on its development. Young people played a key role in the development of all the resources produced as part of the project, especially in the development of content.



### 3. WHY IS TALKING ABOUT SEX, INTIMACY AND RELATIONSHIPS IMPORTANT?

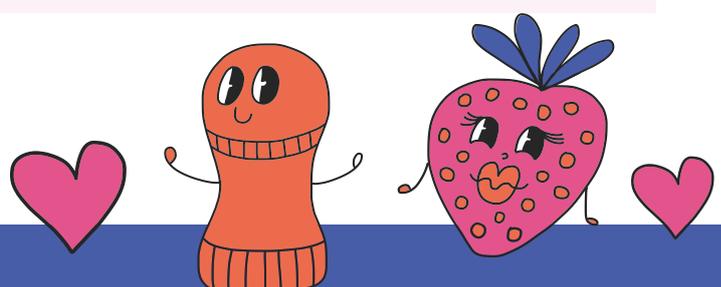
Due to advances in medical treatment and care, increasing numbers of young people with LLTCs are surviving into adulthood (Beresford and Stuttard, 2014). However, a growing body of evidence suggests that they are not always equipped to do so, and that there is an absence of tailored support in the important area of sex, intimacy and relationships (The Open University Sexuality Alliance with Together for Short Lives, 2020).

Many authors suggest that young people experience a period of heightened self-exploration during adolescence, where they question who and what they are, take risks and amplify their social experiences (McGeeney, 2013). Making friends, having relationships and exploring sexuality is an important part of this transition for most young people (McGeeney, 2013) regardless of circumstance. Recent work suggests that establishing and maintaining relationships contributes significantly to the emotional wellbeing of young people and can reduce feelings of social isolation and depression (Abbott and Carpenter, 2016). Recently, TfSL CEO Andy Fletcher stressed the personal and social costs of social isolation and the importance of tackling loneliness for young people living with LLTCs and their families (TfSL, 2018). This project goes some way to speak to this issue by focusing on an aspect of the Pentagon of Support that is often neglected by practitioners and service providers.

Young people with LLTCs report that socialising, having friends or being in an intimate relationship is an important part of growing up and having a 'normal' life (Earle and Blackburn, 2020a). But this group of young people have anything but a normal life. Barriers to education, housing, employment, social and community life mean that opportunities for learning about relationships and exploring sex and intimacy are almost non-existent. Talking about sex is seen as difficult or embarrassing; and many people still consider it to be private or taboo (Richardson, 1998). In the context of young people whose lives are shortened, these conversations can be even more difficult. Indeed, recent research suggests that these conversations often never take place (Earle and Blackburn, 2020b; Blackburn, 2018). Some research suggests that an absence of sex education can actually harm young people, leaving them unable to recognise, protect themselves, or report abuse (NCB, 2016). Disabled children and young people are more vulnerable to abuse than their non-disabled peers, making this topic especially important for them.

Sex, intimacy and relationships are central to all four phases of the transition journey, but we recognise that there is an unmet need and an absence of services and support in this field. Research shows that many family members, carers and professional staff do not feel equipped to develop services that meet these needs (Blackburn, 2018).

Transition is not a new phenomenon. However, our awareness of the needs of young people with life-limiting and life-threatening conditions (LLTCs) has evolved over recent years as they have become older and increasingly empowered to express their views. It has become apparent over several decades that considerable work is required to support the transition of young people with LLTCs who are reaching adulthood when previously they had not been expected to live (Fraser et al, 2013). The Pentagon of Support (TfSL, 2015) illustrates the many important issues to be addressed. The Sexuality Alliance highlights that there is very little support for young people to discuss sex and sexuality and few resources available to parents, carers, organisations and practitioners that will enable them to address this important topic (Blackburn, Chambers & Earle, 2016; Blackburn & Earle, 2015). Young people say that it is a subject that is important to them but often neglected or considered too difficult to talk about. This project has supported young people to talk about sex. It has also supported practitioners to develop their skills and knowledge in working with young people in order to deliver better services.



# 4. DEVELOPING RESOURCES FOR YOUNG PEOPLE WITH LLTCS

The project aimed to develop resources that would support young people to talk about sex and relationships with their family, carers or professional support staff and to equip practitioners to provide better support to young people through knowledge, resources and a better understanding of the views and experiences of young people themselves. The main objective of the project was to produce a set of resources that would be freely available online to a global audience. To this aim a set of five resources were produced:

- **An interactive** [Let's talk about sex, intimacy and relationships...](#)
- **A top-tips listicle** [Nine top tips on talking about sex... for young people with life-limiting or life-threatening condition](#)
- **A short article** [Five things to know about being disabled and LGBTQ](#)
- **A booklet** [Talking about Sex: A booklet for young people with life-limiting or life-threatening conditions and their carers](#)
- **A short film** [Intimate not Intimidated: It's Time to Talk about Sex](#)

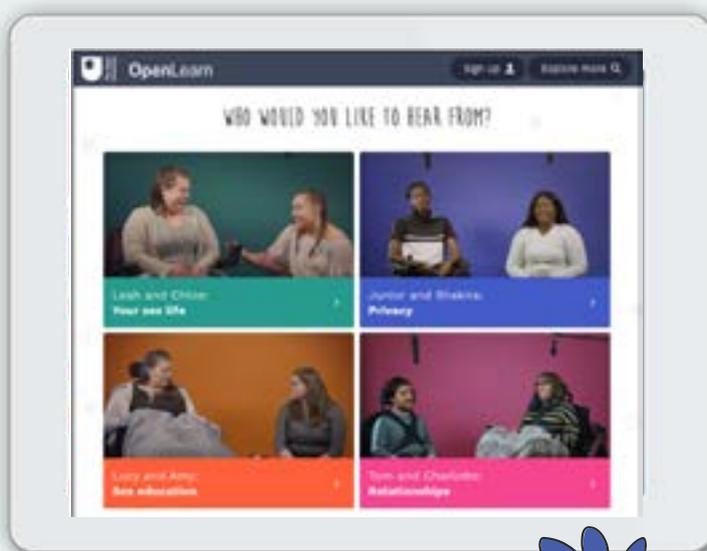
All of the resources are freely available on the Open University's award-winning global learning platform OpenLearn. The booklet is also available as an A5 printed booklet and can be requested from [Together for Short Lives](#).

## LET'S TALK ABOUT SEX, INTIMACY AND RELATIONSHIPS... INTERACTIVE

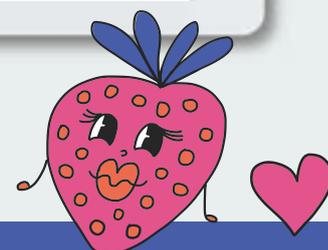
This multi-media interactive video experience explores the challenges around sex for young people who are disabled and/or LLTC. It features six young people/adults with LLTCs (Amy Frounks, Lucy Watts, Charlotte Hardwick, Tom Hardwick, Hameed (Junior) Jimoh and Leah Booth, and two of their supporters (Chloe Booth and Shakira Jimoh) who share intimate aspects of their lives in relation to four topics: sex lives, privacy, sex education and relationships. In each topic area, participants are able to hear from young people themselves and, through a range of interactive questions and answers, explore their own thoughts on sex and intimacy. There is a short survey at the end of the interactive encouraging participants to reflect further on their experiences of talking about sex and on the interactive itself; this short [survey](#) forms part of our project evaluation.

The storyboard for the interactive was designed in collaboration with young people. They helped us choose the topics to cover in the interactive, giving us a framework of 'key areas' to address that were then focused on within the OERs. Some young people contributed directly to meetings with the interactive designers, *Elucidat*. Other young people commented on various versions of the storyboard as it was being developed. Young people also worked with the production company *Tilt* to decide on how the materials would be filmed.

This interactive resource was launched at Hospice UK's National Conference in November 2019 in Liverpool, UK – a recording of this presentation can be viewed [here](#).



Screenshot from the 'Talking about... sex and relationships' interactive

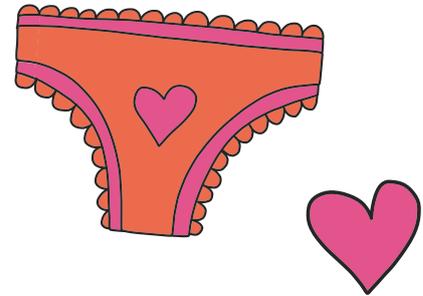


## NINE TOP-TIPS FOR TALKING ABOUT SEX... FOR YOUNG PEOPLE WITH LIFE-LIMITING OR LIFE-THREATENING CONDITIONS

In this listicle, Sarah Earle and Maddie Blackburn collated together many of the suggestions and ideas put forward by members of *AdversiTeam* to create nine top-tips for talking about sex. We asked young people for their own 'top tips' and the sort of tips that would have been useful for them. The listicle offers straight-talking advice and features young people talking about sex in several bite-sized video clips.



Screenshot of the 'Nine top tips on talking about sex...' listicle

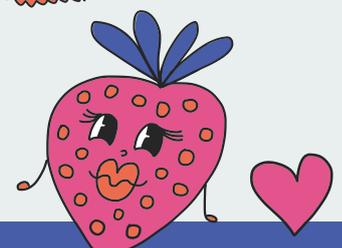
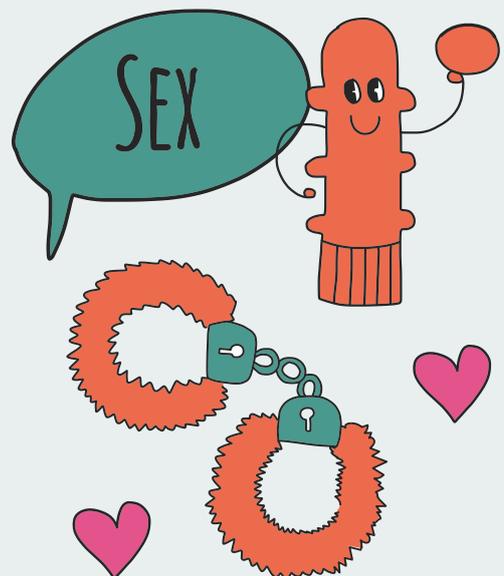


## FIVE THINGS TO KNOW ABOUT BEING DISABLED AND LGBTQ ARTICLE

In this listicle, This short article, written by *AdversiTeam* member Jamie Hale, seeks to dispel some of the myths about being disabled and LGBTQ including the assumption that disabled people are not sexual or interested in sex and, that when they are, that they are probably straight. Jamie highlights the diversity of sexual identities within LGBTQ communities and – drawing on their own experience – acknowledges the additional challenges that young people might face when they are disabled and trans (such as not being able to have surgery due to anaesthetic risk). Jamie highlights the fact that we can only be responsible for ourselves and our own happiness and cannot worry or take responsibility for the feelings and reactions of other people.

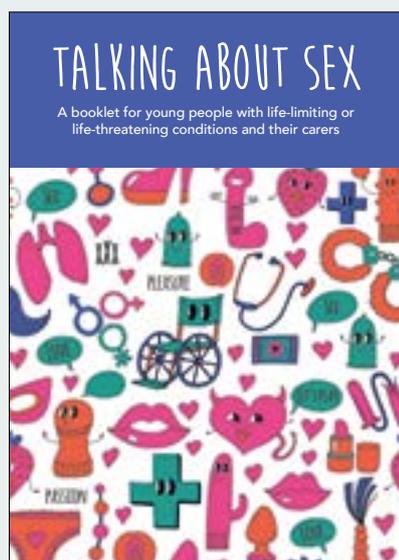


Screenshot from 'One of the five things to know about being disabled and LGBTQ' article



# TALKING ABOUT SEX: A BOOKLET FOR YOUNG PEOPLE WITH LIFE-LIMITING OR LIFE-THREATENING CONDITIONS AND THEIR CARERS

The 'Talking about Sex' booklet is designed to be used by young people and to support them to have conversations about sex, intimacy and relationships with carers, family members and professional staff. It is organised into four key topic areas: 'Thinking about sex', 'Believing in yourself', 'Challenging stereotypes and assumptions' and, 'Expressing your needs'. In each topic area there is information for young people and some 'top-tips' to support them with starting a conversation. There is also a section specifically for carers and another section (for young people and carers) which very briefly signposts to 'what the law says'. The booklet also contains a short glossary of key terms and some additional resources. It is available on the OpenLearn portal as a downloadable pdf, as well as in hard copy. By the end of this project (31st October 2020), 500 booklets had been distributed to individuals, organisations and service providers. On the back cover of the booklet there is a link to a short [survey](#) which is part of the project evaluation.



Front cover of 'Talking about Sex' booklet



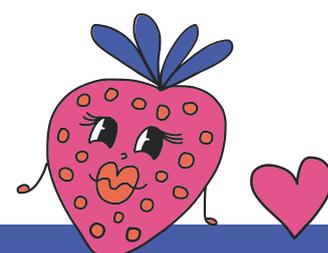
Section 1 of the Talking about Sex booklet: Thinking about sex (for young people)



Section 1 of the Talking about Sex booklet: Thinking about sex (carers and the law)

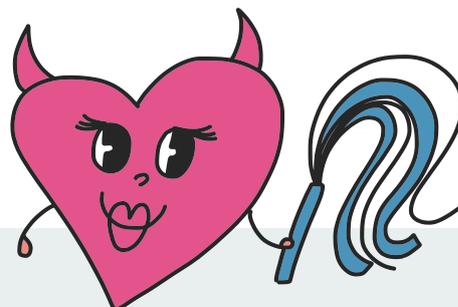
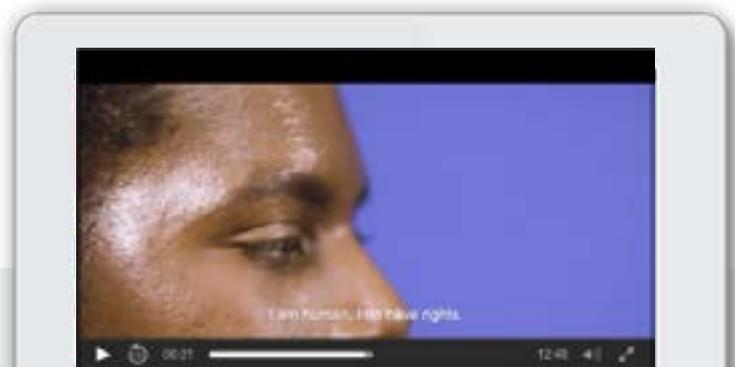
The booklet was developed by members of the project team in collaboration with *AdversiTeam*. Members of *AdversiTeam* provided initial input into the development and design of the booklet and then contributed throughout by providing feedback on numerous drafts. Indeed, we did not originally set out to develop this particular booklet. Our original intention was to create a booklet focused more on the needs of carers. However, overwhelming feedback from members of *AdversiTeam* guided us towards the production of a resource that was not only young-person led, but designed to be used by young people in collaboration with their carers, rather than the other way around. The difference is, in some ways, subtle but it is an important distinction which places young people at the centre of conversations about sex, intimacy and relationships.

The booklet was launched at the 'How to Talk about Sex' online webinar event in September 2020 and the webinar is available to view [here](#).



## INTIMATE NOT INTIMIDATED: IT'S TIME TO TALK ABOUT SEX SHORT FILM

This moving and, sometimes, humorous 15-minute film once again features Amy and Lucy, Charlotte and Tom, Junior and Shakira, and Leah and Chloe. The film provides a deeper insight into some of the issues faced by young people with life-limiting or life-threatening conditions, in particular: the challenges of initiating and managing a sex life; the need for privacy in order to maintain an intimate relationship; and access to sex education.



### A still from the Intimate not Intimidated short film

Members of *AdversiTeam* contributed to the selection of materials that formed part of this film and provided critical feedback on the rough cut. *Intimate not Intimidated* has been nominated for a Learning on Screen Award for Best Education Film (by a University) 2020; due to the coronavirus pandemic, the award ceremony has been postponed until at least Spring 2021.



# 5. MAKING A DIFFERENCE: EVALUATING OUTCOMES

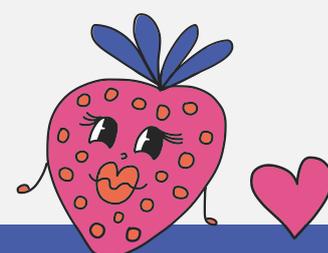
## IN THIS PROJECT WE HAVE EVALUATED FOUR MAIN OUTCOMES:

- (a) the numbers of people and organisations that have used the project resources and the impact these have had
- (b) the impact that the project has had on young people and their confidence in talking about sex and relationships
- (c) the impact of the project on practitioners and their ability to support young people
- (d) sustainability and supporting transition for young people beyond the project.

### As part of our evaluation methodology, we have drawn on the following:

1. interviews with key project stakeholders (the Chair of *AdversiTeam*, members of the wider Open University Sexuality Alliance group).
2. focus group discussions with young people at key points in project development
3. feedback from individuals who have participated in dissemination or training and development events.
4. online surveys (one survey pertaining to the online interactive and one survey pertaining to the booklet – we have not reported the survey data on the booklet as response was very low)
5. user analytics (from the OpenLearn website via the Elucidat learning platform)

It has been very challenging to evaluate the project from March 2020 onwards due to the coronavirus pandemic. In particular, this has affected our ability to evaluate the booklet, which was developed towards the end of the project. Several planned face-to-face events were cancelled and we had planned to carry out further evaluation at these. Although we have sought to evaluate the resources using online methods the pandemic has created huge pressure on professionals, carers and young people which have made this challenging. Below we describe the project evaluation against the four key outcomes above.

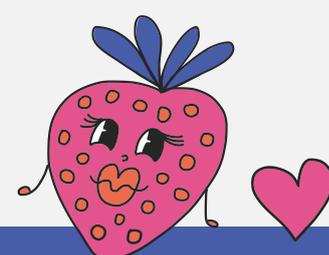


### **(a) The overall impact of the online educational resources**

In this section we report on the user analytics and on the data derived from the online survey on the open educational resources.

By November 2020 4,087 unique visitors made 4,890 visits to the project resources. 563 respondents participated in the online survey although there was incomplete data. The profile of the survey respondents is detailed below (due to incomplete data not all percentages add up to 100%):

- 27% of respondents told us they had a LLTC. 14% of respondents were family members or the partner of someone with a LLTC. 59% of respondents did not have a LLTC.
- 74% of respondents identified as female, 23% as male and 2% identified as non-binary.
- Of those that responded to a question about their age, 22% were between 18-24 years of age and 27% between the ages of 25-34. Only 2% of respondents were under the age of 18.
- The majority of respondents who replied to a question about ethnicity identified as White (87%). The remainder of respondents identified Black (4%), Asian (4%), 'Other' (4%) or told us that they preferred not to say (2%).
- Of the respondents that replied to a question about their sexual orientation, 80% identified as heterosexual and 13% as gay, lesbian or bi-sexual. 4% of those who replied to this question chose not to tell us about their sexual orientation.
- In the survey we asked a number of questions designed to measure the impact of the online educational resources on users.
- **76%** of all respondents agreed that sex and intimacy is important to health and wellbeing
- **64%** of respondents said they were more likely to initiate conversations about sex
- **76%** of respondents said they wanted to find out more about sex, intimacy and relationships
- **59%** of respondents said they felt more confident when talking about sex, intimacy and relationships
- **89%** of respondents said they felt more informed about disability and sex after completing the interactive
- **88%** said the resources had changed their views about disability and sex.



## **(b) Making a deep impact on young people**

In addition to the impact we have reported in the section above, the project has also made an *immediate* and significant difference to the 18 young people that are members of *AdversiTeam*. As part of our evaluation methodology, we interviewed the Chair of *AdversiTeam*, Lucy Watts, who offered her thoughts on how the project has made a deep impact on the lives of young people. In preparation for her interview, Lucy had reached out to members of *AdversiTeam* to ask them about their experiences too:



*'I think that's been really powerful for the young people to have their voices heard and to feel like someone cares about what they have to say was feedback that I got a lot from the young people.'*

*What also made the project and the young people's involvement was the willingness and the openness of the whole team to learn from the young people, to give them that power, to share that power and there was no hierarchy in our involvement... it didn't matter if you were a nurse or a researcher or whatever that person might be, the young people were on a level all the time with them.*

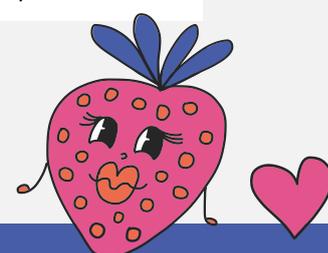
*...sexuality and disability and life-limiting illness is not a topic that people talk about. It's not a place where there's a lot of work and it's not a place where there's a lot of work that's led by young people. It's very much done to, done for, rather than done with and the young people relish the opportunity to say actually, this is what we need, this is what we want, this is what matters to us so you know, it's that nothing about us without us kind of ethos. Young people wanted to be in control [and] have the [agency] what they needed and what mattered to them and we gave them the opportunity to be involved in a way that reflected their wishes and needs but also reflected the things they wanted out of our work. Then, not only to do that in a group of people that absolutely understand what you're doing but actually be able to make a change to benefit your peers. That was a really powerful feeling for these young people.*

*We were a community, and that community was quite important... That community gave them a sense of privacy and confidentiality because they knew they were amongst friends and amongst people that understood them. There's young people that didn't know each other and perhaps people that have met me or met through me or through the *AdversiTeam* that I now see, you know, commenting on each other's posts on Facebook or tweeting each other on Twitter or perhaps that other person's got another project and will reach out to some of the people in *AdversiTeam*, say hang on a minute we're doing this piece of work with this charity, would you like to get involved and it's become a springboard for a lot of other things but I think because we've built that sense of community and mutual respect at the beginning, not everyone's going to be friends and not everyone's going to stay in contact but those people that they felt comfortable with, those friendships were forged quite tightly and I see them continuing and I also see those young people are going off and doing other things together as a result of the working together on this project.'* (Lucy Watts, *AdversiTeam*)

What resonates most strongly here is the feeling of being valued and of being of value to others. For some young people being involved in this project was the first time that they felt they were being heard and the first time that they felt they were doing something useful that might benefit other people in society. Leah Booth, co-chair of *AdversiTeam* describes what being involved in the project has meant to her:



*...for me it was because, I struggled through a lot of my sexuality a lot, through understanding sex and desires and needs and my disability for me this project means that I can give back so what I struggled and fought to learn I can ensure that other people don't have to go through that, I can ensure that there are resources out there so that people can easily access it.'* (Leah Booth, *AdversiTeam*)



Being part of this project also enabled some young people to forge new friendships and to move on to other activities and projects.

Specifically, about the booklet another young person said:

|| *There has been no preparation. No conversations, even when I talked with my nurse co-ordinator about getting married. No support with positioning (something I need, including during sex). Nothing like any of those things. I don't know how I'd ask them, because I'd need them to be offered to me. I'd need someone to start the conversation. In an ideal world, I'd have: discussions with physios about range of motion and positioning for different sexual positions; discussions with occupational therapists about positioning aids, supports, how a hoist could be used etc; discussions with psychologists about the impact of invasive treatment on one's sexual identity and how to navigate a body that feels like medical property; and, access to a network of disabled people talking openly about the practical and emotional aspects and access to sex. But this? This isn't an ideal world – but a booklet like this will hopefully help open up discussions.'* [Contribution of young person to Webinar] ||

### **(c) Making a difference to practitioners and carers**

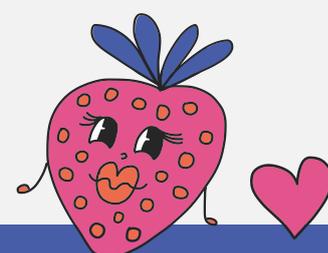
The project aimed to support practitioners and carers to talk about sex, intimacy and relationships with young people. Even when young people feel confident enough to talk about sex and relationships, those conversations can sometimes be shut down by carers, parents, and professional staff who do not always feel competent or comfortable enough to have that discussion. As one of the (young) participants in the online survey said: *'I don't have a problem discussing sex, it's the audience not wishing to engage'*. Our aim is to ensure that none of those conversations are ever shut down and that young people have the opportunity to talk, ask questions and to feel valued and informed.

After the launch of the online resources, the project team became involved in the delivery of training and development opportunities for organisations that support young people in transition, this included hospices, NHS Regional Palliative Care Groups and local authorities/councils. Between July 2019 and October 2020, we participated in 20 training/development events involving approximately 250 individuals (after March 2020 all events were online due to the coronavirus pandemic). These events were always held at the request of the organisation, demonstrating the ongoing need for training on issues relating to sex and relationships. The feedback from these sessions was always overwhelmingly positive and generated rich discussion of the challenges faced by practitioners working with young people in transition. For example:

|| *Very interesting and informative session. It has definitely built on my knowledge and confidence about talking about sex and loving relationships with young adults.'*  
[Feedback from training & development event]

*'With your informative session and... your website, I feel more confident to speak to our target group.'* [Feedback from training & development event]

*'Thank you for being open, honest, and not afraid to talk about the process of sex/ rights/feelings. Look forward to researching the links (to the Open Educational Resources) on handout.'* [Feedback from training & development event] ||



The training and development provided organisations with support for their staff and, as the comments indicate, participants were encouraged to explore the project resources further and in their own time. We also held an online webinar event designed to launch the booklet (September 2020). Many participants commented on the importance of the project having been led by young people themselves and on the visibility of young people's voices within the materials themselves. For example:

|| *Thank you so much for being so honest and giving young people/ adults a voice, but also for educating professionals to open up the conversation and enable others to access much needed support.' [Feedback from Webinar] ||*

One member of the Sexuality Alliance described the way that she used the resources in practice to support the needs of a young man:

|| *we sent home the links to the online resources that yourselves had created and he was able to view those in his own time before the session with the wellbeing practitioner. He'd never been able to talk to anybody about development, about how he was feeling, about his attractions towards people... If I'm honest, it exponentially opened up conversations, conversations about his health, conversations about children, relationships, marriage. [Interview with Sexuality Alliance Member] ||*

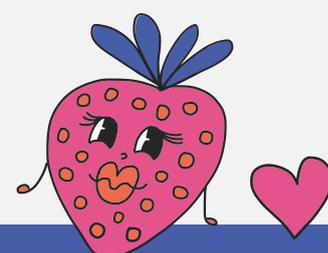
Since the launch of the booklet, we have not been able to participate in any face-to-face events due to the coronavirus pandemic and so we have not been able to evaluate the impact of the booklet as fully as we would have wished. Response to the online survey on the booklet has also been very low, probably for the same reasons. However, as part of our testing and development of the booklet, 10 practitioners commented on the content and design of the booklet and made the following positive comments:

|| *I like how the booklet is encouraging, while contextualising young people's desire and sexualities in the realms of rights, justice and access.'*  
*'I think the flow of the booklet is good taking the reader through practical issues like questions to ask and supporting it with the what the law says.'*  
*'It is very queer-friendly and inclusive of LGBT+ identities. This is FABULOUS to see as this is a serious omission in guidance for disabled young people's sexual education. ||*

We also received some critical feedback which we sought to take on board in the final revisions to the booklet. Some of the comments made in this regard included:

|| *I think something needs to be added here about young people also having the right to parent.'*  
*'As the booklet covers sexuality as a whole, I feel the front cover is quite sexualised with the pictures of sex toys.' ...have further emphasis on relationships, pleasure, passion, touch, love, companionship, etc. ||*

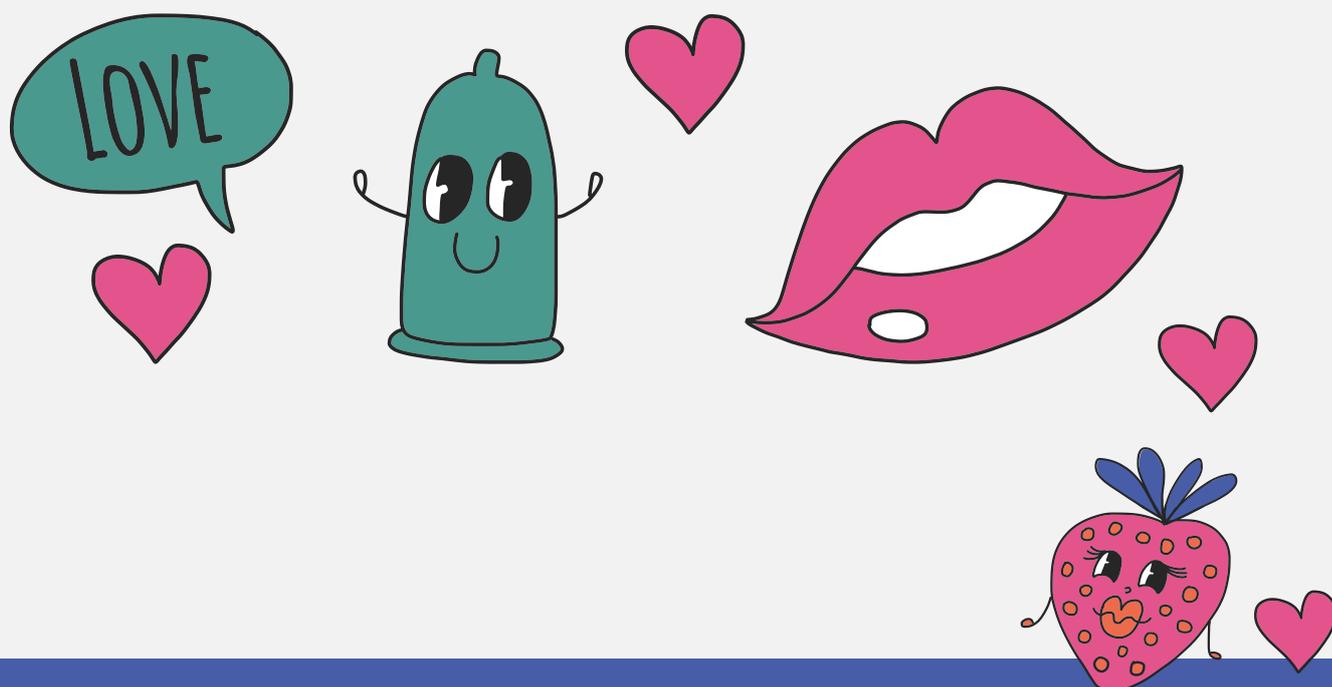
Although these comments only give a snapshot of the feedback from practitioners and carers, overall, the resources are having a positive impact on the ability of this group to support young people in transition.



#### (d) Sustainability and supporting transition for young people beyond the project

It is vitally important that projects such as these build in measures to ensure that its outcomes have a lasting effect on the transition of young people for years to come. We have sought to achieve this through various methods and outline these below:

- When young people are involved in leading a project, they become the project's greatest advocates. They are also the most powerful resource to support long-lasting change. The young people directly involved in the project have themselves talked about the impact their involvement in the project has had on their lives and on the lives of other young people that they know.
- The project was developed as part of the work of the Open University Sexuality Alliance, in partnership with Hospice UK, and funded by Together for Short Lives. Together, the reach of these organisations is extensive and enables us to embed the outcomes of the project within the everyday activities and services of other national organisations. For example, the online educational resources have been embedded into the training and development SEND materials produced by the organisation Brook. Mencap have also recently partnered with us to develop an easy-read version of the Talking about Sex and Relationships booklet suitable for people with learning disabilities which will be freely available as a downloadable pdf from the OpenLearn website in 2021. The online educational resources have also been included in one of the Open University's major teaching modules *Introducing Social Care* (K102). This module – which is part of pre-registration health and social care training – will be available to students until 2027 and during this time, thousands of students will access the materials from our project.
- A robust project dissemination and impact strategy enabled all members of the project team to communicate about the *Talking about... sex and relationships* project at all stages of project development and delivery. All project team members attended speaking engagements, gave papers and organised workshops and other events to ensure that the outcomes of the project were widely disseminated and would have the widest impact on the professional communities that support young people with LLTCs in transition. The project team took part in over 30 national and international engagements between 2018-2020. Opportunities for dissemination and engagement in 2020 were restricted from March onwards due to the coronavirus pandemic although at the time of writing (December 2020), the project team had already accepted requests to participate in a number of (mostly online) events in 2021.
- The project team have also been involved in the delivery of training and development opportunities for organisations that support young people in transition. Prior to the project end date of October 2020, the team had delivered 20 training events. At the time of writing, the project team had accepted requests to develop or contribute to future training in 2021.



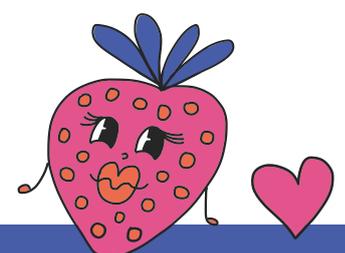
## 6. LESSONS LEARNED

As with any project there are things that we wished we had known about at the start, and things that we might do differently if we were to start all over again. Below we list some of the lessons learned based on our own observations as well as from feedback given directly by young people on the project.

1. Working in multi-professional and multi-disciplinary teams requires patience, a willingness to listen and to flex your position. Sometimes teams have to **agree to disagree!**
2. Co-production with young people means that those involved must recognise that there is a power shift, and that decision-making must be **shared and negotiated**.
3. Engaging with young people who have complex needs requires **careful planning** and, even then, sometimes the unexpected happens and teams must **adapt quickly** to manage any situation.
4. Co-production is **resource-intensive**, particularly when you are trying to work inclusively with groups of people with very diverse and complex needs.
5. When you are working with young people who often experience isolation due to illness and disability, it is important to **build in social time**, as well as work time.
6. Meetings and events must take place in buildings that are **fully accessible**.
7. Young people should be **open and honest** about their personal health and medical needs so that these can be planned for and met appropriately by the project team.
8. Many young people will **need considerable support** to enable their participation especially if they have limited work experience or are trying out new things for the first time.
9. If you are working with young people who are life-limited or life-threatened, there will be times when they cannot contribute to the work because they are too unwell or in hospital. **Your group of young people must be large enough** to ensure that a project can continue to meet its milestones even when individuals are unavailable to participate.
10. When **co-production is peer-led**, young people have told us that this created feelings of equality and security which enabled their participation and collaboration on the project.

Working with young people may not always be easy, especially when you are working with a group with severe, complex and multiple needs. However, we have learnt that it is absolutely worth the investment, input and the time it takes to facilitate co-production at every level. Lucy Watts says:

|| Our project would not be as rich and impactful had the young people not been so involved and invested in the work. It was more than just 'you said, we did', it was about working together, as a team of people from various backgrounds and experience, to create the best resources to have the greatest impact. This went beyond consultation to true co-production in every aspect of the project. We also now understand the value to the young people of being involved: the skills, knowledge, confidence and self-belief they have developed through being involved, having power shared equally and their voices and contributions not just being used, but truly valued and integral to the project. ||



# REFERENCES

Abbott, D. W. F. and Carpenter, J. S. W. (2016) **"The things that are inside of you are horrible": Children and young men with Duchenne muscular dystrophy talk about the impact of living with a long-term condition**, in Kelly, B. and Byrne, B. (eds) *Valuing Disabled Children and Young People: Research, Policy, and Practice*, Routledge, pp. 143–153.

Beresford, B. A. and Stuttard, L. (2014) **'Young adults as users of adult healthcare: experiences of young adults with complex or life-limiting conditions'**, *Clinical Medicine*, vol. 14, no. 4, pp. 404–408 [Online]. DOI: 10.7861/clinmedicine.14-4-404 (16 December 2018).

Blackburn, MC (2018) *Sexuality, relationships and reproductive choices in young adults with life limiting and/ or life-threatening condition*; PhD thesis, The Open University.

Blackburn, M., Chambers, L. and Earle, S. (2016) 'Talking about sex, relationships and intimacy: New guidance and standards for nurses and other health and social care professionals working with young people with life-limiting and life-threatening conditions', *Journal of Advanced Nursing*, vol. 73, no. 10, pp. 2265–2267.

Earle, S and Blackburn M. (2020a) Young adults with life-limiting or life-threatening conditions: sexuality and relationships support, *BMJ Supportive & Palliative Care* DOI: [10.1136/bmjspcare-2019-002070](https://doi.org/10.1136/bmjspcare-2019-002070).

Earle, S and Blackburn M. (2020b) Involving young people and adults with life-limiting conditions in research on sex: The intersections of taboo and vulnerability, *International Journal of Social Research Methodology* (early online).

Fraser, L. K., Miller, M., Aldridge, J., McKinney, P. A. and Parslow, R. C. (2013) 'Prevalence of life-limiting and life-threatening conditions in young adults in England 2000–2010', *Final Report for Together for Short Lives*, York, Department of Health Sciences, University of York. Available from:

[http://www.togetherforshortlives.org.uk/assets/0000/6736/TOGETHER\\_FOR\\_SHORT\\_LIVESAdultReport2013Final.pdf](http://www.togetherforshortlives.org.uk/assets/0000/6736/TOGETHER_FOR_SHORT_LIVESAdultReport2013Final.pdf).

McGeeney, E. (2013) **What is good sex? Young people, sexual pleasure and sexual health services**: PhD thesis.

National Children's Bureau ([NCB] (2016) *Heads or tails? What young people are telling us about SRE*. London: National Children's Bureau for the Sex Education Forum.

Richardson, D. (1998) 'Sexuality and citizenship', *Sociology*, vol. 32, no. 1, pp. 83–100.

TfSL (2015) *Stepping UP*. Bristol: TfSL. Available from:

<https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/02/ProRes-Stepping-Up-Transition-Care-Pathway.pdf>.

The Open University with Together for Short Lives. (2020) *Talking About Sex, Relationships and Intimacy: Guidance and Standards for Those Working with Young People with Life-Limiting and Life-Threatening Conditions*, The Open University and Together for Short Lives. Available from:

[https://www.open.edu/openlearn/sites/www.open.edu.openlearn/files/tassr\\_very\\_final\\_web\\_151119.pdf](https://www.open.edu/openlearn/sites/www.open.edu.openlearn/files/tassr_very_final_web_151119.pdf).

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