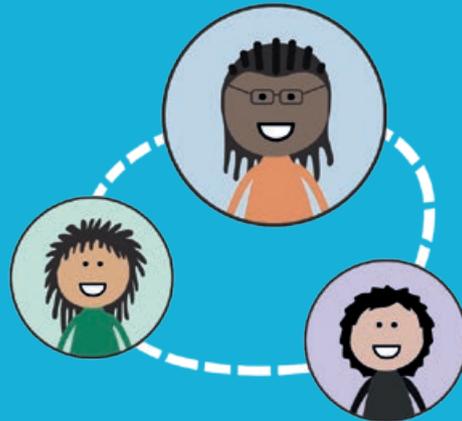




University of  
East London

**RIX.**

# RIX Research & Media 2020



Hello!





**RIX Research & Media Team**

Back row: Gosia Kwiatkowska, Craig Wilkie, Ajay Choksi, Kanchan Kerai / Front Row: Charlie Minnion, Andy Minnion, Richard Lohan, Jo Finch  
*RIX team member Sam Goncalves is not in the team photo, but she is featured in the Parent's Perspective article on page 13*



**Front cover**

Artwork by Charlie Minnion inspired by Adjoa Weidemann, a co-researcher on the purpleSTARS advisory team and a member of the Tower Project in East London

# Welcome!

Welcome to RIX Research and Media 2020, our annual update for friends, colleagues and newcomers about the activities of the RIX Centre at the University of East London.

We are excited to be able to share an expansive range of stories about the array of activities we undertake with our many partners and organisations. What these activities have in common is that they all feature the positive impact that multimedia advocacy can have for people with learning disabilities and their families. Beyond that, they illustrate the many and varied ways in which our software and methods are being applied – whether this is to transform museum experiences so that they are more inclusive or to help social work trainees engage with young people who communicate without speech.

The experience of enabling learning disabled people to have their voices heard is transformational. It is great to read about the different ways in which our work has helped people to build communication and understanding. The account of our UEL students overcoming their anxieties about working with people with high support needs and learning to appreciate that ‘these are such beautiful individuals’ is inspiring.

In our work at RIX we repeatedly see how the use of our tools and methods can help to overcome communication barriers and connect us together more effectively as citizens – surely a critical project in these adversarial times. Our involvement with European colleagues on the ‘MYS – Me and Your Stories’ project exploits this effect in a new and exciting way.

This work is broadening the reach of multimedia advocacy to challenge the prejudice and misunderstanding that can result from young people failing to connect with others in the classroom who are different. The MYS method uses creative story telling and retelling to share our unique and different experiences of culture, faith, gender and ability. It is an opportunity for the RIX team to share our software and training with a broader range of people and to see once again how enhanced self-advocacy and self-expression can be a force for good and a cause for celebration.

I hope you enjoy the stories and voices that summarise our year in these pages and that you will share our enthusiasm for the potential of technology to enrich our human connections and make the services we offer more effective, building a society that we can all share and enjoy.



Andy Minnion MBE

**Director**

RIX Research & Media

**Professor of Media Advocacy**

University of East London

*P.S. You can point the camera on your smartphone at the code on the back page to visit our RIX Website – and while you're at it, think about how we could use this kind of tech to help make the Web more accessible for people with learning disabilities!*

# Wikis in Wales

## 'Building confidence, communication and self-belief'

Young people with learning disabilities and autism are pioneering Wikis in Wales as part of Powys County Council's response to the challenges laid down by the Welsh Government in the Additional Learning Needs and Education Tribunal (Wales) Act 2018. The Welsh Act shares aspirations with England's SEND Reforms – to increase the participation of children and young people in the shaping of their care and support.

This means making sure learners' views are always considered as part of the planning process, along with those of their parents and carers. The Act spells out the importance of children and young people experiencing personal planning that is done **with** them and not **to** them.

The potential of RIX Wikis to enable this to happen has already been evidenced with local young people, parents and teachers. Katie, from Llandrindod, is the first Welsh resident to be awarded a Wiki Champion certificate after presenting her Wiki to local council

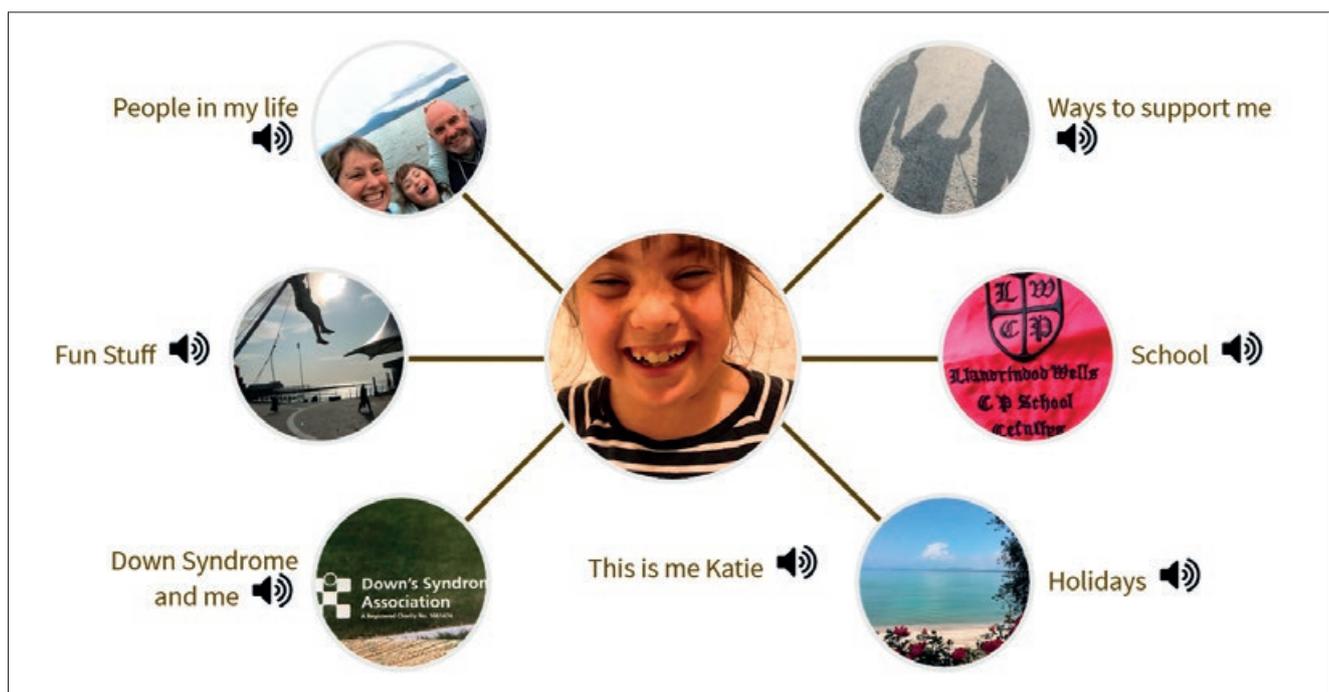
leaders. She is one of 11 local RIX Wiki Champions demonstrating and promoting multimedia advocacy to excellent effect across the county.



Powys County Council's Wellbeing worker, Rhys Williams, attended Katie's recent review meeting, which he described as being 'by far the most child centred review that I have been part of' due to Katie's use of the RIX Wiki. Independent Speech and Language Therapist, Zein Pereira tweeted that she was 'blown away by how RIX wiki tool enabled a genuinely child led review

meeting'. Vince Barnard from the Sensory Service sees its potential to 'help pupils of all ages develop into valued members of the community, building confidence, communication and self-belief.'

A Welsh language version of the RIX Wiki software has been developed for the Powys project and the learning and evidence from this is being shared by the Powys team with 5 more local authorities across mid Wales as part of the ALN Transformation programme.



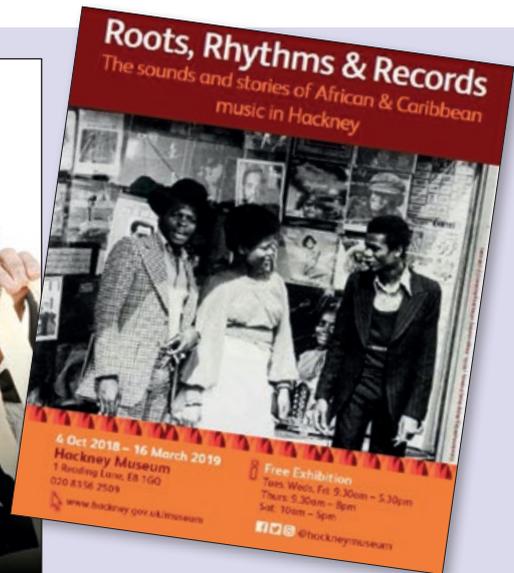
Welsh Wiki Champion Katie's RIX Wiki homepage

# PurpleSTARS and the Pride of Place project with Hackney Museum



The RIX Centre hosts the purpleSTARS, a mix of artists and technologists with and without learning disabilities who work with museums using electronics, media and sensory art to help make the visitor experience more inclusive. In 2019 the purpleSTARS

worked with the Hackney Museum in response to the **Roots, Rhythms and Records** exhibition that showcased the rich presence of African and Caribbean Music in the Borough since the 1950s. This photo-story charts the methods and achievements of the project.



▼ The team liked the old-school styles that went with the music. It reminded them of their parents and grandparents, their stories of immigration and their cultural roots

▲ The purpleSTARS chose to work on Hackney Museum's Roots, Rhythms and Records exhibition because they are major fans of black music – and Paul lives in the Borough

◀ Before they visit the show they review publicity material, research the themes explored in the display and make personal connections

**Fashion and Style** 🔊

What brings music together is the style and fashion to the culture of african and caribbean music from years back.

**Worldwide sounds** 🔊

We are Rufaro, Lee, Paul and Santino - here with Emma from Hackney Museum. We are posing with the 808 beats machine at the Museum.

The 808 beats machine that we are looking out is used for records and drums plus its an amazing technology to practise music and to do beats.

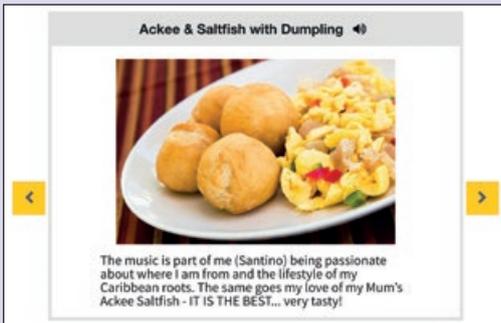
▲ They met the Museum's curator at the exhibition, took photos of the displays that caught their attention and used the Wiki to document and reflect on the experience

▼ A Windrush tea party at Hackney Town Hall inspired the team with the stories they heard, alongside the music, food and clothing and the display of flags from Caribbean nations



▲ They built a new Wiki to organise their retelling of the exhibition's themes with a personal, sensory and accessible emphasis

▼ The team developed these themes with a sensory focus, comparing their experiences of the tastes and smells of their own families' cooking and its links to their own roots

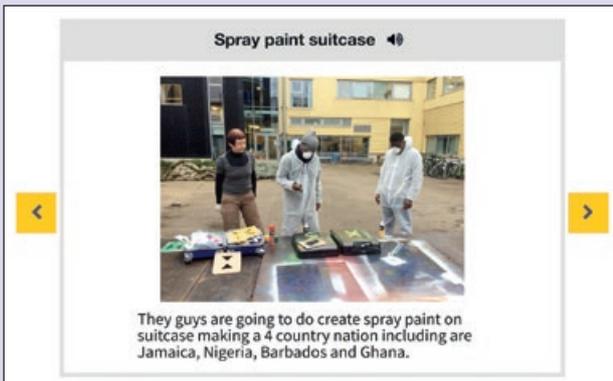


They produced music, raps and poems with community music & media group Raw Material, re-interpreting the exhibition's themes and linking with their own musical tastes

▼ They made artwork for vinyl, cassette and CD versions of their recordings, using flags to portray their heritage



They produced models of jollof rice, chicken, peas and dumplings for interactive display



◀ The team created a suitcase for their sensory handling objects and decorated it with the flags of the countries from which their families came

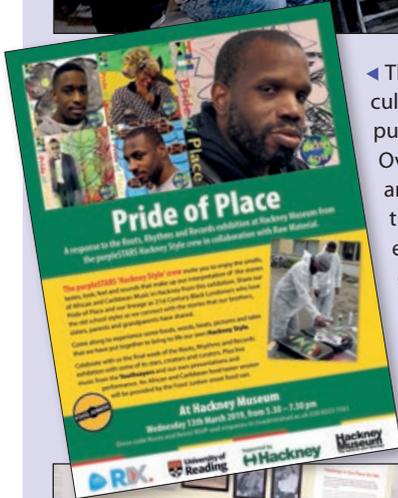
▶ They used a photoshoot to explore styles from their heritage and showcase their artwork



They worked with local disabled adults in the Advanced Art Group to create their own Jamaican sound system installation



▲ The STARS worked with Hackney rapper Badladee to provide workshops for local school children at the exhibition



◀ Their work culminated in a purpleSTARS Take Over event with food and performance on the last day of the exhibition, which coincided with World Disabled Access Day

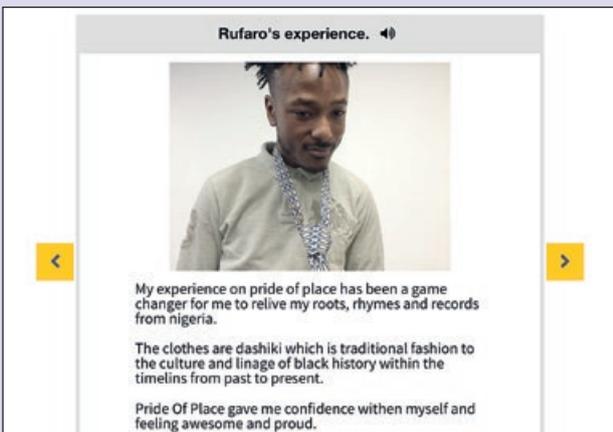


◀ They shared their sensory objects and retold the stories that inspired their creation

▼ The team performed raps, poems and a DJ set. Judith wore Kente cloth from Ghana and the men chose the styles of the African and Caribbean performers of the 60s and 70s



▼ After the Event the team used their Wiki to capture what the Pride of Place project had meant to them...



...and Judith joined the volunteer team to work as a receptionist at the Hackney Museum!

## An interview with three NHS clinicians

**Thanks for joining me today everyone and, first of all, could you introduce yourselves and say what your job is?**

**Carys:** I'm Carys and I'm a learning disabilities nurse.

**Emine:** My name is Emine and I'm an occupational therapist and I specialise in learning disabilities.

**Elyse:** And I'm Elyse and I'm a speech and language therapist and I specialise in working with people with learning disabilities.



### Where do you work?

**Carys:** I work for CLDS [Camden Learning Disabilities Service] and I'm based at Alexandra Centre which is Camden's college for adults with PMLD and Autism.

### What age are the students at Alexandra Centre?

**Carys:** It would be 16-25 years old.

**Emine:** I work alongside Carys at Alexandra Centre. We do a lot of work in people's homes as well and we also do transition work. So if they're going to leave the college and they're moving on to a day service, we make sure the transition is graded and goes smoothly.

**Elyse:** I also work in Camden's learning disability service – I work with adults, so 18 upwards, in the community. That means I might work with people in their homes or in day services, I may go out into hospitals to see them, wherever they are I'll go and see them there.

### How have you all used RIX Wikis in your work?

**Elyse:** I've used Wikis in a few different ways. I've been using them as a training resource – I do a lot of training and I've used a Wiki as a resource to teach

people about eating and drinking difficulties and how to support communication. This means that parents, support workers and tutors can access support materials whenever they need to.

### Do you use the Wiki to deliver your training, like a presentation?

**Elyse:** No, I tend to use it more as a handout – everything that goes into my PowerPoint, I've broken down into sections of the Wiki. I'd give people access to that once they've been to my training, using the Invite button.

### So people go away from your training and they have this online resource which has all of the information that you've shared with them in the training?

**Elyse:** Yes, and it's really useful because we can update it as a new evidence base emerges so it's always relevant. Also, we've recently created a resource for students so that any new research they've come across in their studies, I add it to the Wiki. This is really helpful for new students who've come into the service – there's a section on learning disabilities, a section on eating and drinking, a section on communication etc... I've also used a Wiki as a communication profile for one of my clients with sections on being out in the

community, likes and dislikes, communication and things like that.

### And who would you share that with?

**Elyse:** That would be shared with the person and the people supporting them – all the information that a support worker or family needs to support that person is accessible and in the Wiki.

### Emine, how have you used Wikis in Alexandra Centre?

**Emine:** I've used Wikis as part of review meetings, so that when we have these twice yearly meetings we upload information to the Wiki and send it to parents and carers, SEN co-ordinators and social workers. It's a good way of displaying the work a person has done, the progress they've made and any therapies they've taken part in. I do a lot of sensory work at Alexandra Centre and a Wiki is a really good way of looking through sensory diet recommendations and also evidencing this by showing videos of the progress a person has made. Other practitioners and therapists also use Wikis in this way in the college.

### Would you share the Wiki with other staff in the college so they can contribute to it?

**Emine:** Absolutely. The Wiki is owned by the tutor who will be constantly updating it until the student leaves, at which point the Wikis are passed on to the families. It's a real joint effort.

### Carys, how have you used Wikis?

**Carys:** At Alexandra Centre we also use Wikis for students who are now leaving, with all of those sections about how to care for them, things that they like, how to communicate with them, that will accompany them to the next stage of their life – so if they're moving on to day services or employment, anyone working with them will know exactly what to expect and how to support the person to reach their full potential. The Wiki can save a lot of time and is really key for information sharing and consistency. It means a person or their family carer won't have to keep repeating themselves.

### What Wiki features do you particularly like?

**Emine:** I like the fact that you can have different sections, it's really easily laid out, accessible, really

clear and for parents who don't have English as their first language you can have pictures – it's really user friendly!

**Carys:** Aesthetically, they're really nice to look at – a spider with bubble shoes! It's really good that, without specifically saying it, it forces you not to write in jargon so that you're writing that information in a way that's accessible for every single person that could be reading it. Nursing reports can come across like essays a lot of the time, so the Wiki can make this information much easier to read.

**Elyse:** I like all the visual aspects, being able to upload videos – so if you want to show an example of a really effective communication where people are using really simple information, using Makaton signing or something visual like that, you can show it in a video. You can also upload pictures – I will often take photos of resources I've created like communication tools and include a bit of information about them.

### Do you have any suggestions about how the Wiki software might be developed in the future?

**Emine:** I have to upload quite a lot of videos and I have to get people to video my sessions and that's not always planned. If the video clips are the wrong way around it doesn't work so well on the Wiki. I wonder if there could be a way of cropping or zooming in on a portrait style video so it takes up more of the screen.

**Carys:** We've all been saying how accessible the Wiki is but it's only accessible through a browser. If it could be put into an app so that everyone could have it in their phone and could travel with it, that would be better for me.

**Elyse:** I would like to be able to copy and paste a slide from one section into another section – sometimes I've had to restructure the content of a wiki and this has felt time-consuming and harder than it should be. Also, when you're in a section and you want to create a new slide, and maybe you want it to be the second slide along, it will automatically put it in at the end – it would be much quicker if you could choose where it should be and it just got inserted there.

Thank you very much everyone and keep up the great Wiki work!

## Multimedia advocacy in action – Supporting learners with communication challenges

Social Work students from the University of East London have gained invaluable knowledge and experience working on a Wiki building project with learners at Charlton Park Academy. The students worked in pairs with young people with profound and multiple learning disabilities to help them develop their Wikis. The Wikis would be used to capture their communication, share their thoughts, their likes and dislikes and their aspirations. This is part of a six month *Advocacy Pathway* on a *Readiness for Practice* module that is offered to UEL Social Work trainees each year by the RIX Centre team in partnership with Charlton Park Academy.

The students shared their fears with us at the start of the module as they met learners who were non-verbal and had complex support needs. One student, Louise, explained, *"I was a bit overwhelmed; I felt a bit helpless. How am I supposed to communicate if they are non-verbal? How will I understand? How am I going to create a Wiki for them that is theirs if they are not able to tell me what they want?"*

Another student, Kaitlin, shared her colleague's nervousness but both were also really excited about the prospect of learning new ways to communicate with these learners using the multimedia advocacy approach. Over the weeks of Wiki building work, the Social Work trainees built understanding relationships

with the young people. A highpoint for Kaitlin was when the learner she was working with started to communicate with her by reaching out for her hand, smiling and meeting her gaze.

Working with photos and video clips and steadily building a portfolio that captured the communication of the learners gave the undergraduates some valuable insights. Kaitlin explained that she could now appreciate the importance of being able to communicate with individuals who do not use speech. *"As social workers we are there to support them. We have to learn to communicate with them and advocate for them and not be scared of their level of ability."* She felt that working with non-verbal people should be mandatory training for every social worker.

The experience of doing multimedia advocacy work alongside learners with high support needs has helped to transform the Social Work students' perspective on disability. As Louise sums up, *"It's been humbling actually. Over the weeks I really did learn that, actually, they are telling me so much, even without verbally communicating. So, yes, I would say it's definitely a great experience for everybody to have. Even though he's non-verbal, I've been able to communicate with him and understand what he wants. These are such beautiful individuals and sometimes that's missed!"*



The graduates with their certificates

# RIX EasySurvey – Capturing the views of everyone

**Craig Wilkie reflects on the development of RIX EasySurvey and reveals some of the secrets behind the planning and production of RIX’s newest accessible software tool**

We started by looking at the very best features of survey tools that people already use and then made these features easier to use. As with the RIX Wikis, we based this approach around the use of rich media and easy to understand text alongside the image or video. The text-to-speech function also helps make this software genuinely accessible.

We also understand that survey creators want to be able to pull together a survey quickly, so we added a cloning tool. This allows the user to duplicate an existing survey and adjust the questions as required. We also added drag and drop functionality, allowing survey creators to put images and videos in their survey in seconds.

Understanding how people feel about a course, activity, service or product is really important and



*Ajay discussing Easy Survey options with the Purple Stars group at the end of a teaching session*

EasySurvey is a great way to capture this feedback so organisations can improve their services and products.

The process of creating and developing the software has been an exciting journey for the RIX team – now it’s time for organisations, schools, charities, local government, social care and healthcare providers to make the most of this accessible tool to truly understand the views of the people who matter most.

## **RIX EasySurvey Founder Members Offer**

To celebrate the launch of EasySurvey, RIX are offering a limited number of Founder Member accounts. Founder Members will be given a special EasySurvey discount, with the ability to create unlimited surveys and receive unlimited responses. In addition, Founder Members will be invited to special RIX EasySurvey events, have access to masterclass training opportunities and help shape the future development of EasySurvey.

You can find out more about EasySurvey by visiting the RIX Research & Media website where you will find further details, with case Studies from local authorities, schools and charities.

To start a free trial or to buy EasySurvey please contact us at [rixadmin@uel.ac.uk](mailto:rixadmin@uel.ac.uk)

# Ten top tips for making **Easy Surveys**

Use our handy tips to think through your survey before you begin to create it. Planning your survey will improve the quality of the responses you get. This will help you to get a better understanding of the views of your voters.

SEN event EasySurvey feedback plan		
Questions about	format	answers
1 venue	rating scale	5 options
2 presenters	multiple select	choose 3
3 catering	single select	add text entry
4 learning	ranked list	6 themes
5 suggestions	free text entry	tell us more

## 1 Plan your survey

Decide what it is that you are trying to find out more about and then work backwards by thinking of the best questions to draw out this information from people.

Did you enjoy the food today?  
Single select

Which meal did you choose?  
Single select

Did you have a dessert?  
Single select

Which dessert did you choose?  
Single select

## 2 Organise your survey

Use sections to organise your survey. Try to group similar questions together as this will help the voter to go with the flow. It can be helpful to plan out the sections on paper or sticky notes.

Easy Survey survey

Would it be useful to have videos in surveys?

yes, that would be so cool!

no, what would be the point of that?

Back Next

## 3 Know your voters

Think about your voters and design your survey in a way that works for them. Use pictures and videos to get the voters' attention and keep them interested.

Kiosk, open to all  
Invite only  
Kiosk, open to all

Skip logic active   
Show section headers

Survey questions - drag and drop to change their order

Is this page easy to understand?  
Single select

Edit Clone

## 4 Kiosk mode

Keep your survey short and focused as people may be taking the survey in 'kiosk mode', the feature that allows you to set up a survey in a public space automatically collecting and resetting the survey for new voters.

Is this page easy to understand?  
Single select

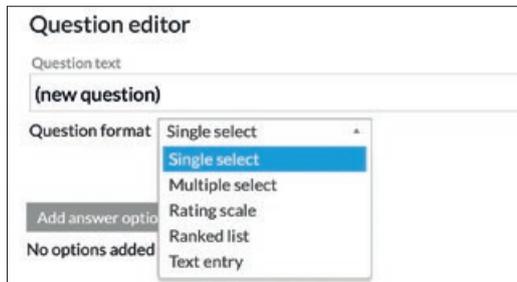
How would you rate this as a survey tool for our clients?  
Rating scale

Would it be useful to have videos in surveys?  
Please rank these outcomes in order of importance for the people we work with  
Ranked list

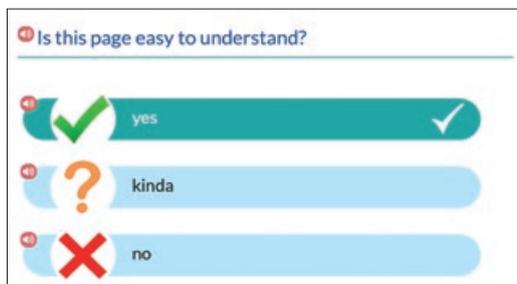
## 5 Prioritise questions

Make sure you ask the most important or useful questions close to the start of the survey. It is easy to change the question order of your survey with drag and drop.

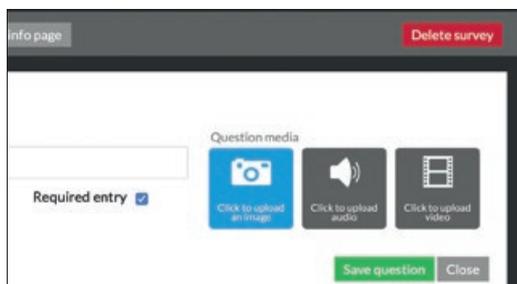
- You can find the EasySurvey user guide on our website:  
**[rixresearchandmedia.org/rix-easy-survey](http://rixresearchandmedia.org/rix-easy-survey)**
- Frequently Asked Questions can be found here:  
**[rix-wiki-help-desk.groovehq.com/help/rix-easysurvey-frequently-asked-questions](http://rix-wiki-help-desk.groovehq.com/help/rix-easysurvey-frequently-asked-questions)**
- To start a free trial or buy EasySurvey today please contact us at:  
**[rixadmin@uel.ac.uk](mailto:rixadmin@uel.ac.uk)**



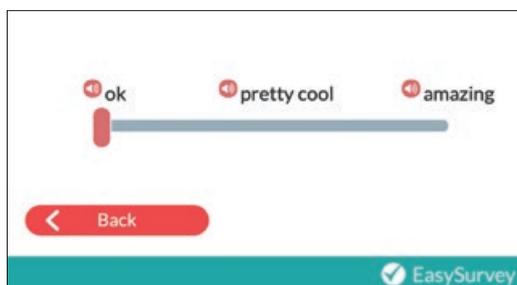
**6 Mix it up** Use a mix of question types to keep your survey engaging and fun. EasySurvey has 5 question types to choose from: Single select, Multiple select, Rating scale, Ranked list and Text entry.



**7 Keep it simple** Try to keep words to a minimum if you want your survey to be as inclusive and accessible as possible. Avoid jargon and difficult words, keep sentences short and choose images which support the words.



**8 Images, audio and video** EasySurvey allows you to add video, pictures and sound to every page of your survey. Along with words, these different media can help the voter to understand the survey question and respond with confidence.



**9 Easy navigation** An EasySurvey is easy to complete and intuitive to navigate with its next and back buttons on question pages. As users move backwards and forwards through questions, their answers are automatically saved.

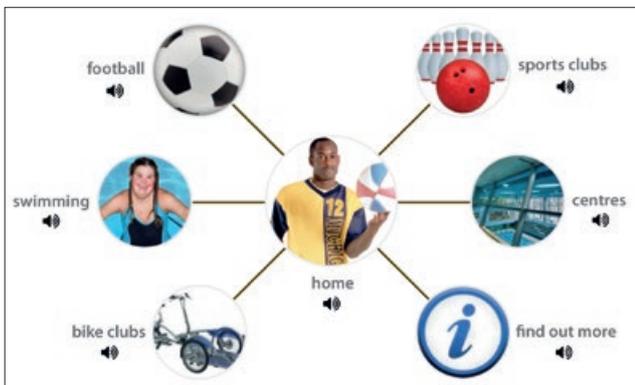


**10 Understanding the results** Once the survey is done you'll want to understand how people responded to your questions. EasySurvey displays results using word clouds, text and numbers. Results can be exported into an Excel spreadsheet.

# RIX Wikis and easy read, best of friends



The RIX Wiki is a great way of providing people with accessible information because it lends itself so well to the easy read format. Service information from a local authority can be made more user-friendly in a public Wiki, person centred information about how to support someone can be shared with families and support workers in a clear illustrated guide that can be easily updated.



Homepage for a sports Wiki

The RIX Wiki format lets me map out themes on a symmetrical mind map which serves as my website's homepage. The homepage is uncluttered and easy to navigate, with lots of white space. If my section circles have short titles and attractive images the page looks even better.

Once inside a section circle we are in slide format, a great fit for the easy read approach:

one idea = one sentence = one picture = one slide.  
If there are two ideas I might need two slides. Think of it as bitesize chunks, you still get to eat the whole apple (get the full story) but do not suffer indigestion (confusion).

Language – the words we use – is key in any easy read format, so I try to avoid long words where a short one will do (**hard** not **difficult**, **plan** not **strategy**). I replace the official with the everyday (**said** not **stated**, **person** not **service user**) and am wary of conjunctions (**although**, **but**, **and** etc.) as they introduce a second idea into a sentence.

I write dates in full without the superscript (14<sup>th</sup>, 3<sup>rd</sup>) like this: Monday 2 December 2019 and I split phone numbers into pairs like this: 020 79 74 25 63 or 079 60 08 88 63.

I use punctuation sparingly – does a single sentence on a wiki slide need a full stop? And there's something about The Over-use of Capital Letters that jars with my easy read sensibility.

Pictures and videos form an essential part of the Rix Wiki and, just as with language, these should be easy read too! Pictures that are clear, easy-to-understand and support the message, and videos the same – short and snappy, bitesize chunks. And finally, audio that is audible and clear – I'm excited about the prospect of a RIX Wiki app where my device's native software can read out text for me, clear as a bell!

The design of easy read material carries an important message. The person with learning disabilities is entitled to the same quality of information design as everyone else. And if we can get it right for the people who face the most barriers, we'll be getting it right for everybody. The design of the clean, colourful and carefully laid out easy read page has found a new friend in the simple and easy-to-use RIX Wiki. This software can help us meet the standards of accessibility for our information provision that we aspire to.



Wiki slides as bitesize chunks

## Parents' Perspectives

### About Me information sharing

Sam Goncalves has been a longstanding multimedia advocacy pioneer with her son, Shane. Sam and her family have worked with the RIX Wiki since we first developed the software in 2012. Here she describes a year that held significant challenges for Shane as he made the transition from school to adulthood in his local community. The year has also provided unique opportunities for Sam to share the benefits of a multimedia approach both at the Professional Records Standards Board annual meeting and the Association of Directors of Adult Social Services annual conference.

Having a RIX Wiki for my son Shane for the past seven years has helped us promote a person centred approach to information sharing. It has always been my view that good care and support can only be achieved through the sharing of the right information, the kind that's typically not available in a professional report. Knowing my son Shane has cerebral palsy will not give you the information you need to understand his communication and how to support him effectively. Not understanding Shane's idiosyncratic signs and expecting to give good support is like reading this article in another language and expecting to understand it.

Seeing my son experience a placement breakdown and the devastating impact of poor support has impelled me to speak up and share our story at a



Sam presenting her Story at the PRSB advisory board meeting



Shane's Wiki page documenting his gardening skills

national level. Challenging behaviour was blamed on 'learning disability' and 'environmental issues'. We, like many parent carers, do not like the term 'challenging behaviour'. I'm interested in the barriers to positive behaviour. On reflection it was clear to our family that the barrier to positive behaviour was the lack of understanding of Shane as a person and the poor levels of information sharing within the organisation. Too much emphasis was given to my son's diagnosis and difficulties and not enough to his communication, capabilities and potential.

Too often we hear professionals hiding behind GDPR without fully understanding its requirements and their responsibility. The Information Governance Review of 2013 tells us that 'relevant information should be shared with members of the care team, when they have a legitimate relationship with the patient or service user'.

(continued on next page)

It is vital that care providers understand what matters to people with complex needs. Sharing the importance of **About Me** information with the Professional Records Standard Body (PRSB) Advisory Board in April 2019 gave me the opportunity to highlight the impact of not sharing relevant information. It also allowed me to showcase the improved level of support and care which can be achieved through knowing and understanding how a person likes to be supported and live their life.

Speakers from ADASS and NHS Digital gave us a social care perspective on digital, data and technological developments within the adult care sector – a perfect introduction to our story. The RIX Wiki has enabled us as a family to effectively share all of Shane's communication, health and care needs alongside his wishes, views, feelings and aspirations which are captured through pictures and videos.

It was good to be able to contribute views to the Professional Records Standard Body's Core Information Standard that defines exactly what information should be shared in a person's care record throughout their life.

The PRSB's Core Information Standard survey of NHS staff, patients and carers in 2019 evidenced that over 80% of participants thought '**About Me** information should be prioritised as part of the core information record.'

[theprsbannualreport.org/core-information-standard](https://theprsbannualreport.org/core-information-standard)

A highlight for me this year was being invited to speak at the National Children and Adult Services Conference in Bournemouth. It was a privilege to present alongside David Watts (ADASS) and Dame Fiona Caldicott on a person centred approach to information sharing.

Dame Fiona reminded everyone of the seventh Caldicott principle: *"The duty to share information can be as important as the duty to protect patient confidentiality"*. Let's not forget the intended outcome of the Care Act – for people's wellbeing, needs and goals to be prioritised so that individuals no longer feel like they are battling against the system to get the care and support they need. If we continue to hide behind GDPR and put up unnecessary barriers to information sharing, how can people like my son Shane be supported to live life to the full?

## Seeing the world through Katie's eyes

**Katie and her family from West Sussex started creating a RIX Wiki in June 2016 when the family were invited to be part of an exciting pilot scheme trialing the benefits of multi-media advocacy.**

Through having the RIX Wiki, the family discovered that Katie's vision wasn't fully corrected by wearing glasses.

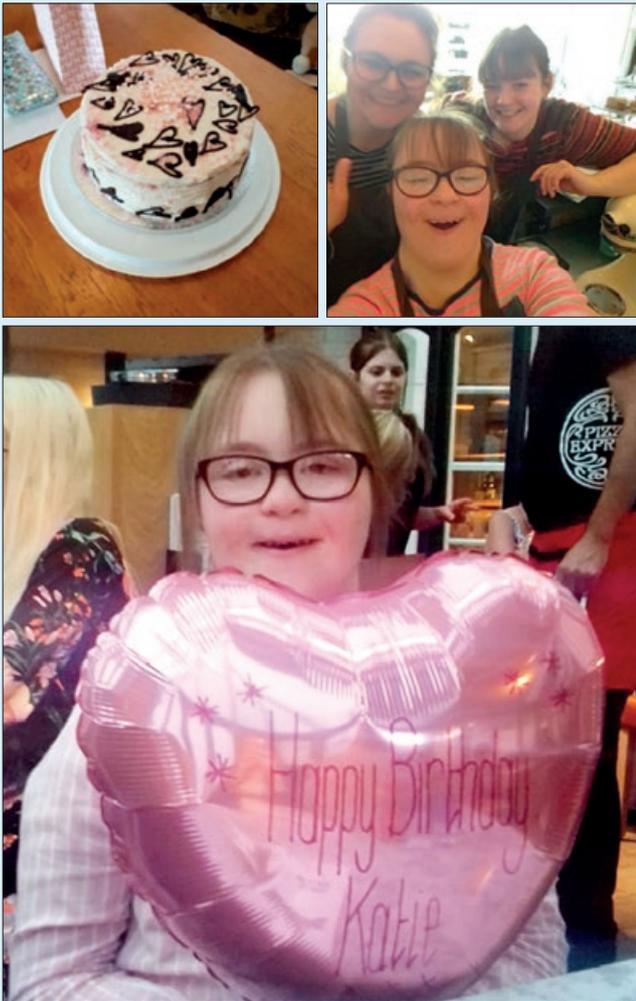
At a routine optician appointment Katie's mum, Rachel, asked how she could show Katie's school how her visual impairment affects her. The optician placed lenses on Rachel's eyes that replicated Katie's vision without glasses and Rachel could not see any of the letters on the board. The optician then placed the lenses that replicated Katie's vision with her glasses on and Rachel had to really concentrate to read the top line of letters on the optician's board. She was shocked to learn that Katie could only read the 2nd or 3rd line down, as nobody had previously explained to the

family how Katie's vision would affect her everyday life and learning. Past struggles had always been put down to cognitive ability, due to Katie's diagnosis of Down syndrome, whereas now it was clear that her vision also had a large part to play.

*"I didn't realise that she couldn't see the second line clearly, as she lives in a world of fog."*

RACHEL, KATIE'S MUM

The family decided to dedicate the first Section of their RIX Wiki to Katie's visual impairment. It was important to the family that those working with Katie could understand how she sees the world and how best to support her.



Katie on work experience at 'Baked' community café in Worthing and celebrating her birthday in 2019

Katie's mum got in touch with Dr. Maggie Woodhouse at Cardiff University, an expert on Down syndrome and how visual impairment affects education and daily living skills. The family received literature about how Katie sees the world, as people with Down syndrome struggle with contrast and clarity of vision. This information went straight onto the Wiki along with her suggestions for the font and font size that Katie's resources should use.

Dr. Woodhouse also sent the family a filter which replicates the best that Katie can see the world. This meant that if you couldn't see something easily whilst placing the filter over your eyes then neither could Katie. The family were able to use the filter to make videos of homework that Katie had been given to show how Katie saw it and the difference it would make if the wording was enlarged and formatted in bold.

Learning about the RIX Wiki and being able to present these vision videos has had a big impact on

securing the right support for Katie. After sharing Katie's Wiki with all the school staff, modifications and adjustments were made and a referral to Sensory Support was supported.

*"If I had just written an email trying to explain about Katie's vision, the impact and outcomes would not have been the same. Staff would have questioned me, as they can see Katie in lessons looking at the board and just put the slow pace of copying and reading down to having Down syndrome".*

RACHEL, KATIE'S MUM

Katie's GP was also invited to view the Wiki and a low vision assessment followed, which in turn gave Katie a referral to a Rehabilitation Officer for the Visually Impaired, Mark Brownlow. Mark was also invited to view Katie's Wiki, before he came to meet her.

By then Katie had made a 'welcome' video and the Wiki was personalised in pink, her favourite colour. Mark looked at the Wiki prior to the first meeting and noticed Katie's passion for pink and although he didn't own any pink trousers, he did wear a nice pair of burgundy jeans. He was also able to get a good picture of who Katie is as a person. If she wasn't as bubbly as in her welcome video, and had her head down, this meant that she was understandably just a bit shy. She wasn't reacting in this way because she has Down syndrome and 'that's what they do'.

Mark also picked up on her passion for baking so the assessment started in the kitchen and they talked about baking and Mark brought a few gadgets and suggestions that would make baking easier for her. The result was that Katie wasn't shy or nervous and they struck up a great relationship from the beginning. When it came to the symbol cane training, Katie was no longer nervous. Mark was impressed with the Wiki,

*"I thought it was a really good way to gain a wealth of information about Katie that would have taken so much time to obtain face to face. I could access Katie's low vision assessment, see videos on how her eyesight affects her ability to read print and see what text size she can read. I could then easily access a link to what Katie likes to do in her spare time, school life, and aspirations for the future. I feel that it gave a great insight into Katie's life. All in all, it was a great benefit to have access to this."*

MARK BROWNLOW (ROVI)

# Family carers and the RIX multi me toolkit

A highlight for RIX in 2019 was meeting a team of family members and professionals in Oxfordshire who have been trained to use RIX Wikis as part of a new multimedia advocacy Toolkit that we have co-developed with the software company, **multi me**. Alongside schools, colleges and care agencies, the Oxfordshire Family Support Network is helping us to implement multimedia advocacy across the county, using the new Toolkit with people who have complex support needs and their families. Here family and professional trainees share their own account of this pioneering work.

## **Gail – Programme Manager, Oxfordshire Family Support Network**

We are all family carers, experts by our own lived experience.

A group of parents had done the person-centred planning course beforehand [and had] basic understanding of person centred thinking and some of the tools that they could use, which fitted absolutely perfectly with the multi me software. The RIX Wiki is somewhere to put your PCP, somewhere to store all that information that you've gathered that [you] need to go in a plan to focus on the detailed stuff together. The Wiki in multi me gives you that place...

## **Jessica – Parent**

I wanted to do the multi me training because I think it's a fantastic way for people who are working with Imogen to understand her needs and what's important to her. She can't communicate with words, so the videos and the photos that we can put on with multi me are fantastic for her.



*Multi me's Charlie Levinson with the trainees at the Oxfordshire Family Support Network workshop*

## **Jo – Parent**

I wanted all Edward's stuff in one place so I don't lose anything and so people, when we go through transition, can find it all in one place

## **Angeli – Parent**

I wanted to do the training because of the person centred approach that fundamentally underpins it

## **Angeli – Parent**

How many times have you turned up at a paediatric appointment and they haven't been able to get the file... that has happened to me so often. With a Wiki, just hand your phone over and go 'I'm really sorry that you haven't got your file... but here's a start!'

## **Silvana – Parent**

Apart from keeping records, which has been immensely beneficial for me, this is an amazing communication tool. [Cara] is verbal, she can speak. But it has to be alright for people to tune in and to take longer. She is at the stage where she is trying to be independent of me – which is amazing! Yet so far those people have seen only certain facets of this young lady and think she can't do things or think she should be treated in certain ways. This tool has enabled them to see that there are many, many more things that she can do! Sometimes she underplays it and says 'Oh help me!'. They have seen a totally different side of her which means, just in the past 3 or 4 weeks, their relationship with her has gone to a totally different level – and she has gone to that level without any difficulty whatsoever! So, it's been a total boon for her.

## **Lisa – Parent**

One thing that you've got with the Wiki that no other health service brings is video. A video of a weird type of seizure, or of a specific type of procedure with your person – that video is really valuable.

I've seen the value of it when somebody goes into hospital [too]. They often just start again at the beginning with assessment and things like that. It's not as if all the information isn't known, it's just not known to them and they spend 6 months getting to know the person, don't they? [But] with this multi me it's just all there and they can see the person as they are with their family and in their community.

### Hanna – Sister

Nathanael has loads of needs and he is very complex and we always want new carers coming in. But training a new carer takes about three months, so any time you can shave off that three months is great. So, we have made quite a few videos about how to do things. Obviously we can write down things on paper and tell people how to do things, but when routine is this important to our children to get them really happy and keep them safe, you have to be really confident and know exactly what it is that you need to do.

### Laura – Oxfordshire Health NHS Foundation Trust (OHFT)

You get to see the person and we often see people when things are really hard for them. So actually to see what it was like before and see what we are kind of aiming to get back to – it's really helpful!

### Harry – Senior Physiotherapist OHFT

All we get [now] is a piece of paper – just a referral

### Laura – Intensive Support Team, OHFT

Yes, we ask people to fill in a lot of paperwork. We are trying to gather a lot of data and we spend a lot of time asking people to repeat themselves. If we could find ways of adding that to the Goals [tool on multi me],



Cara presents her Wiki

we are making it easy for people – and then we are just pulling it straight off the system and that's going to save a lot more time.

### Sam – Parent

It's just great to connect all the professionals and family together so that we all work together to give Otis the best care that we can as a team really. I think that's what is important – that we work as a team together. With multi me it helps to make that happen – and it's quite difficult to make that happen. So I think this software is really fantastic for that because it does connect everybody together.

## The multi me toolkit

The RIX multi me toolkit combines the RIX Wiki with the following tools



### My Circle

My Circle is a secure social network that serves as the user's support network. It allows the person to share and interact with friends, family and professionals in their circle of support.



### My Diary

My Diary allows users to create and share a daily blog using a combination of photos, videos, words and stickers.

### Buddies

Buddies are key supporters in the user's Circle who can be made into personal gatekeepers with the ability to manage the individual's own permissions on multi me.



### My Goals

My Goals allows users to set and manage their personal targets. Goals are broken down into Tasks that can be scheduled and assigned to different users in their Circle.



### My Calendar

My Calendar gives an easy read and visual overview of a user's weekly activities. This displays as a visual timetable.

# Celebrating 12 years of employment – Wiki Master

My name is Ajay Choksi and I am 39 years old. I started working at the RIX Centre at the University of East London back in 2007. I am a technical assistant and a Wiki Master! I love my job! I teach students how to build Wikis. I travel to and present at national and international events. I do a lot of Wiki testing. I build a lot of Wikis for projects to provide accessible information in an easy to read format.

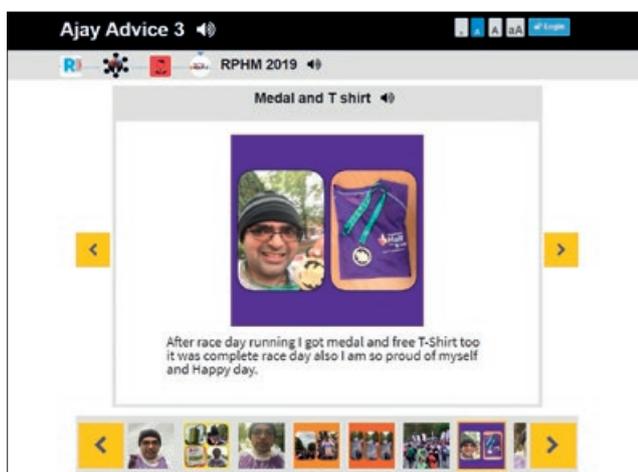
I also have many personal Wikis. My very first personal Wiki was called 'Ajay Advice'; it offered advice to other young people who wanted to be independent. I am now on Ajay Advice version 3. In this Wiki I have many sections and subsections where you can find a lot of information about me, my job, what I like, my goals and my advice. For example, my latest update included my personal wellbeing achievements – I successfully completed a half marathon in October 2019. In my Wiki you can find out about the whole story, from registering for the half marathon, through to training and the actual event.

[wiki.rixwiki.org/Default/home/ajay-advice-3](http://wiki.rixwiki.org/Default/home/ajay-advice-3)

I also have a personal research Wiki, where I keep a diary of my involvement in many research projects, my reflections, observations and my learning:

[wiki.rixwiki.org/rix/home/research-wiki](http://wiki.rixwiki.org/rix/home/research-wiki)

I have many fond memories of working at RIX but one that stands out for me is the time I started delivering training on my own for the first time at the United



Ajay's Wiki, page documenting his achievements



Ajay sharing his Wiki with a colleague

Response training. I taught staff how to use Wikis, it was great and they all listened and learned. My goal is to do more of that! It was nice to receive positive feedback from everyone. Manager, Sarah Frost said: *"When I walked into our Teddington enterprise hub I immediately saw that you were totally in control – very relaxed and confident in an incredibly busy environment. I was just so impressed that the environment felt inclusive – it was a mixed group of people fulfilling very different roles just working together harmoniously. It is inclusion and that's how it should be!"*

I am proud of my achievements and I feel lucky to do what I love. My advice to other people is: You can do it and you can live it!



Ajay presenting in Berlin at MYS project seminar

# RIX co-develops digital social care with United Response

RIX Research and Media first trialled the RIX Wikis with care provider United Response in 2016 and this proved really popular with both their frontline staff and the people they support. We have since worked together to model a vision of how the person centred tools like the RIX Wiki could transform the way United Response use digital technology to provide personalised social care and support. Tim Cooper, Chief Executive of United Response, explains the organisation’s **Social Me** vision that has emerged from their work with RIX.

*“United Response is committed to a genuinely person-centred approach to social care and sees real potential to realise this through the use of digital tools. The people who we support with learning disabilities and mental health issues want to use social media alongside their peers. With the kind of easy-to-use tools that RIX and multi me provide they can do this easily and safely. As a social care provider, we see potential in using these tools at the heart of our information systems so that the thoughts, wishes and aspirations of our clients steer the support we can provide for people to live the lives that they want to live. We have called this digital-enabled approach that we have been developing with*

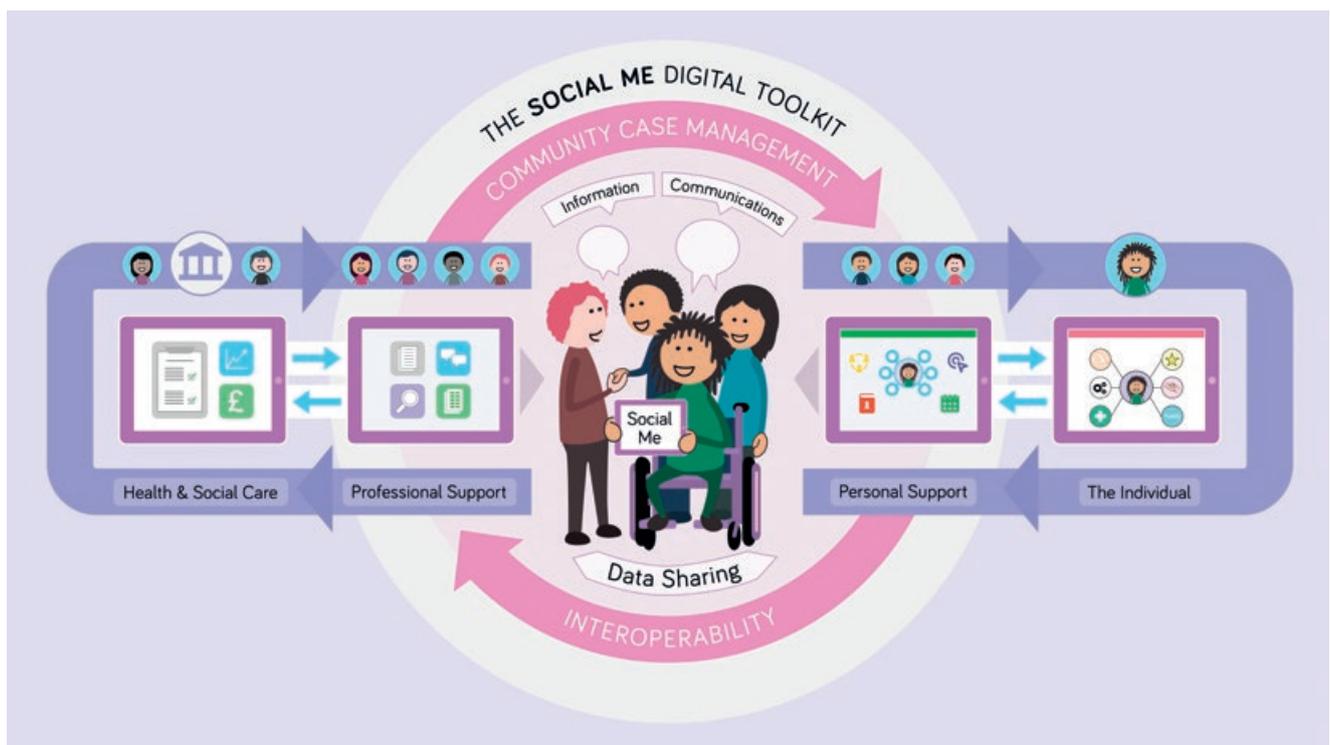
*the RIX Centre team and our users **Social Me** and we are looking forward to co-developing and implementing this vision with the RIX team, the people we support and the agencies that we work with over the coming year.”*

The Social Care sector faces extraordinary challenges in the UK where according to the The King’s Fund 2018:

- there are high levels of unmet need
- there is a lack of investment in prevention and demand
- there will be increasing future demand from both older people and working age adults. (The King’s Fund 2018, Key challenges facing the adult social care sector in England. [www.kingsfund.org.uk](http://www.kingsfund.org.uk) Accessed 9/01/2020)

Our collaboration with United Response aims to prove the concept that a multimedia advocacy approach can improve the quality of person centred care for citizens alongside job satisfaction for frontline care staff and grow business efficiency for provider organisations through improved communication and information sharing.

We produced this infographic to help explain our vision of how the **Social Me** approach will work.





## RIX Wiki shortlisted for 2020 BETT Award

The British Educational Training and Technology (BETT) conference has been

held in London since 1985 and attracts over 35,000 delegates. It is very much an international event focusing on educational technologies.

Along with seminars, training and a huge exhibition of 800 organisations and partners, the BETT conference also includes the prestigious BETT awards.

These awards are categorised into areas such as School Support Services, Best Online Software, Best Small Educational IT Business.

RIX submitted a case study and testimonials for the Wiki software to be entered into the 2020 BETT Awards Special Educational Needs Software category. The award judging panel told us that we had been shortlisted for the finals, thanks to the strength of our submission and the quality of the Wiki software.

The finals, where the winners of each category are announced, take place in Docklands in January 2020.

It is a great achievement for RIX to be shortlisted for such a prestigious Award and welcome recognition for the significant contribution RIX Wiki software can make for people with additional support needs.

## The MYS Project – sharing our stories to build understanding and friendship

RIX Research & Media is part of a Europe-wide project called MYS – Me and Your Stories – which promotes multimedia approaches to sharing personal stories in the classroom in order to promote better understanding between learners of diverse cultures, backgrounds and perspectives. The project partners come from Austria, Germany, UK, Slovakia and Romania. Together we are creating teaching resources and organising seminars and conferences for teachers and policy makers. The three year project is developing and implementing a MYS Toolbox for multimedia storytelling and retelling for inclusive education and to challenge prejudice and misunderstanding. The sharing of personal stories will celebrate the richness of our learners' experiences and the diversity of our communities.

The project will produce schemes of work for schools, colleges and community organisations to use, alongside guidance and instructional materials. Teachers from across the partner countries are being invited to attend training sessions and share their ideas and practice. A shared RIX Wiki portal underpins the project, hosting the work that develops from workshops and the implementation of the MYS tools across our different countries.



Graphic facilitation and teacher delegates at the MYS seminar in Berlin



# About RIX

## Who we are

RIX Research & Media explores and develops ways of using new technologies to transform the lives of people with learning disabilities. We are an international research and development centre at the University of East London.

For over 15 years, we have produced and piloted software, developed working methods and researched the impacts of a spectrum of different ways to use new media to enable social inclusion.

Find out more about the RIX Centre here:

[www.rixresearchandmedia.org](http://www.rixresearchandmedia.org)

## What we do

- We research tools and techniques in the field in partnership with individuals and their supporters, professionals and organisations
- We provide training on effective use of multimedia and the Web for individuals with disabilities and their families
- We develop packages on the multimedia advocacy approach for professionals, parents, carers and individual users
- We sell and support the RIX Wiki and RIX EasySurvey software

You can find out more about RIX software and our subscription, training and support packages here:

[rixresearchandmedia.org](http://rixresearchandmedia.org)

We are open to working collaboratively with you on your projects, please get in touch to start a conversation with the RIX Research & Media team.

## You can find out more about RIX projects here

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### purpleSTARS

Sensory and digital methods to make Museums more inclusive and participatory with a Sensory Expeditions Guide for use with your learners.

[purplestars.org.uk](http://purplestars.org.uk) & [sensoryobjects.com](http://sensoryobjects.com)

### Me and Your Stories – MYS

Developing an inclusive learning approach using the MYS Toolbox, a set of innovative multimedia storytelling resources for schools fostering social inclusion through education.

[wiki.rixwiki.org/mys/home](http://wiki.rixwiki.org/mys/home)

### Multi me

Multi me is a secure social platform for individuals with disabilities and the circle of people that support them in their daily lives.

[multime.com](http://multime.com)



Point your smartphone camera at this QR code  
to visit **[rixresearchandmedia.org](http://rixresearchandmedia.org)**

## RIX Research & Media

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