

GROUP 1. Enabling and Empowering Young Adults with Diabetes

Interventions				
A: Diabetes and DES health information package delivered to young adults with diabetes as written material, video or other AND				
C: Age related peer support groups for young adults with diabetes AND				
M: Training screeners and graders to give immediate feedback to young adults about the findings of their DES.				
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Matthew Cruice	Team Leader Adult Screening Programmes London region			
Stella Ward	Adult Screening Commissioning Manager London region			
Tunde Peto	Ophthalmologist (EROS team member)			
Angel Strachan	JDRF Public Affairs Officer			
Irene Stratton	Statistician (EROS team member)			
Rebecca Thomas	Researcher, University of Swansea (EROS Research Advisory Group)			
Emily Richardson	Young adult with Type 1 diabetes (EROS Public and Patient Involvement panel member)			
Mary Bishop Strutt	Young adult with Type 1 diabetes			
	Prioritized interventions	Barriers and/or enablers that the proposed intervention addresses	Components of the intervention that could be addressed	Issues identified in Event 1 (30 th June 2021)
A	Diabetes and DES health information package delivered to young adults with diabetes as written material, video or other.	A YA with diabetes; <ul style="list-style-type: none"> • does not understand the reasons for attending DES, attending DES becomes more of a priority when signs of complications appear • does not talk about DES or diabetes complications 	Promote awareness about diabetes and DES, including the importance of attending DES, younger people having diabetes, and the difference between type 1 and type 2 diabetes.	<ul style="list-style-type: none"> • Centrally produced information on DES very generic • Tailored communication more likely to be effective than 1 size fits all ('<i>young people friendly</i>') • Information could contain communication of risk of developing diabetic eye disease

		<ul style="list-style-type: none"> • does not know about the treatments available if DR is detected • worries about losing their sight in the future • believes there is a lack of knowledge about diabetes and DES amongst the public and HCPs <p>Representative quotes from YA</p> <p><i>“I didn’t feel that I was given any education on why my screenings were important in the first year or two. So, I went to my first one, didn’t go to my second.”</i></p> <p><i>“I don’t really know much, I just know that either they keep an eye on it for a few years, or you keep going in to see a specialist instead of the regular screenings and then if it gets worse, I think it starts with the laser and then a couple of operations can be done as well I think, but I don’t really know that much about what’s done.”</i></p> <p><i>“What can I do now to make sure that I don’t get retinopathy in the future, rather than just trying to spot it? I know it [DRS] is</i></p>		<ul style="list-style-type: none"> • Messaging needs to be consistent between DESPs and diabetes care providers • Delivered by young adult (YA) or HCP? (Young people respond better to young people) • Very good blogs available for YA Type 1 diabetes • ‘Can never have too much information’ • Need to start early e.g., transition using media more suited to YA (online/social media/linked via QR codes) • Fear of vision loss and may be a risk that raising issue may scare YA and is not a good motivator • Positive messaging (not just stories of what happens when things go wrong. Improvements in glycaemic control have reduced the risk of developing sight threatening retinopathy) • Lots of information out there that could be used or adapted (links to existing resources on appointment letters) • Resources (toolkit) made available to regional programmes to educate YAs, tailored to individuals • Develop a mobile for YA which combines education with appointment booking system <p>CHALLENGES</p> <ul style="list-style-type: none"> • More education may not the answer for YAs’
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C	<p>Age related peer support groups for young adults with diabetes.</p>	<p>Attending DES becomes more of a priority for when signs of potential diabetes complications are identified.</p> <p>A YA with diabetes;</p> <ul style="list-style-type: none"> • does not talk about DES or diabetes complications 	<p><i>Provide information/case studies/testimonials on</i></p> <ul style="list-style-type: none"> • Risks of developing Diabetic retinopathy (DR) and progression using contemporary data • Potential complications if DR goes undetected • Treatments for DR e.g., effectiveness of treatments reducing the risk of DR 	<ul style="list-style-type: none"> • Diabetes absorbs a lot of emotional energy • Let YA know 'they are not alone in this' • Messaging would carry more weight if delivered by someone who has experienced it • Shared experience and provide link to others going through the same experiences • Peer support groups are great at building community and feeling less alone with

		<ul style="list-style-type: none"> • does not know other people their age with diabetes • experiences diabetes burnout (i.e., feeling overwhelmed by the burden of diabetes management) • lacks confidence in disclosing or discussing their diabetes to other people <p>Representative quotes from YA <i>"I do think as well just that, when it comes to the diabetes community that you don't always talk about complications, so that's not the nice side of living with Type 1. So, you can get peer support, but you don't always find people who are openly talking about their complications."</i></p> <p><i>"So, I've literally been probably two years in the past just really burnt out with and overwhelmed by diabetes care and slipped into a pattern of just not taking my medication, not checking my</i></p>	<p>progressing (particularly if caught early)</p> <p>Emphasis on positive rather than negative information to minimise defensive or avoidant responses. Encourage YAs create a positive identity associated with diabetes e.g., something they shouldn't feel ashamed of, feel empowered to talk about on their own terms. Helped by;</p> <ul style="list-style-type: none"> • Observable examples from others disclosing and discussing their diabetes • Suggested scripts/wording/advice of how to disclose their diabetes to others. • Storylines on TV • Social media peer support groups, sharing of tips and strategies amongst YAs <p>Consider facilitation of groups by YAs with diabetes who have experienced DES themselves. Encourage sharing of reasons why do/do not attend, group problem solving and positive experiences.</p>	<p>diabetes. If this is an online support group then I see it having better attendance than face to face. Maybe a mixture is possible but YA do most things online</p> <ul style="list-style-type: none"> • Applies to all aspects of diabetes care • Particular need for support during transition • Social media may help e.g., twitter, blogs, YouTube videos <p>CHALLENGES</p> <ul style="list-style-type: none"> • Experience from cancer screening has identified cultural/ethnic differences in support needed
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M	<p>Training screeners/graders to give immediate feedback to young adults about the findings of their DES.</p>	<p>YA with diabetes;</p> <ul style="list-style-type: none"> needs clearer information in DES results and more support experiences mixed feelings about receiving DES results (e.g., anxiety and relief) <p>Representative quotes from YA</p> <p><i>“To be honest I find it kind of pointless as my Opticians maintains a better, easier access for support and help if I feel there is a problem, also they explain the results the doctors at the screen don’t tell me anything.</i></p> <p><i>“Unknowledgeable screening staff saying everything looks fine then getting a letter stating background retinopathy is very disheartening. “</i></p>	<p>Screeners who are suitably qualified provide initial indication of the likely result at DES appointment, so YAs don’t have to wait 2-3 weeks for results letter. This may involve;</p> <ul style="list-style-type: none"> Further training for screeners with examples of scripts and videos of how to discuss the results in an appropriate way <p>Reinforcement by screener/graders that regular attending DES increases the likelihood of early detection and treatment and reduces the risk of vision loss, and YAs don’t need to live in fear of future blindness</p>	<ul style="list-style-type: none"> ‘Golden opportunity missed’ Also use as an opportunity to discuss diabetes control self-management Provide context to results How do you handle bad news? What support is needed? Real time feedback particularly valuable when progressing from no DR to background DR. Letter often triggers a phone call due to concern Significant training issues e.g., communication but 'scripts' could be developed Can’t be done casually but with appropriate training and the necessary caveats it can make a big difference' Developments in AI may be the answer Images double graded for QA purposes to provide definitive result therefore result has to be 'provisional' If the YA is already worried and lacks knowledge about DES and DR then

		<p><i>“Also no one will tell you anything- what can you see? Is it worse than last year? Is it better? They just say wait for the results and 6 weeks of anxiety later you get a generic letter and leaflet with a grade on it but no details- fine it's background but is it better/worse what is going on with my eyes?!”</i></p>		<p>having someone to reassure them at the appointment would be beneficial but how in-depth will their knowledge go?</p> <ul style="list-style-type: none"> • ‘I feel like a more knowledgeable screener is helpful but won’t make a YA attend their appointment, plus they actually have to go the appointment in the first place to have this conversation’ <p>CHALLENGES</p> <ul style="list-style-type: none"> • Time issues in a busy clinic • Could provide false sense of security or unnecessary anxiety if get it wrong • Screeners don’t grade and would require experienced screener/grader to provide real time feedback • Images viewed on laptops without the resolution used in the formal grading process • Training screeners/graders to give immediate feedback will generate patient complaints
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DES – Diabetic Eye Screening

DR – Diabetic Retinopathy

HCP – Health Care Professional

YA – Young Adult with diabetes (Type 1 or 2)