



# Teenagers and Young Adults with Cancer

*Uniting professionals. Improving practice*



## How to provide and manage social media tools for communication with teenagers and young adults

### TYAC best practice statement for health professionals

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Final Version



# How to provide and manage social media tools for communication with TYA for health professionals

## BEST PRACTICE STATEMENT

*The beauty, but key challenge for professionals and society alike, is the pace of change of the world of social media. Whilst this guide has been written there have already been significant innovations. We have attempted to write this guidance so it can be used with emerging new social media technologies.*

### Scope

To produce best practice guidance including exploring the merits of which media to utilise and what tools are most suitable for peer communication.

### Introduction

If you work in TYA health and social care, then this best practice guidance is for you. Hear about the merits of which media to utilise and how colleagues have overcome barriers, some perceived and some real, to reach out to young people in a medium of their choosing.

In November 2014, in recognition of the impact of social media on the planning, delivery and conversations about healthcare, the NHS Employers organisation launched *New to the NHS: Your guide to using social media in the NHS*.

They firmly believe in a permissive approach to using social media in the NHS. It stipulates that *“individual staff should be permitted and enabled to use social media for work. Only a permissive approach will unlock the innovations within the vibrant creative spaces found on social media sites.”* This is ratified more recently by publication of *On the brink of something special*, a detailed analysis of social media use in the NHS. Most NHS organisations realise it is now *“the arena of choice and activity for growing numbers of patients, families, staff and stakeholders; and the NHS really needs to up its game and begin to use it properly; if used properly it could deliver real value to the NHS itself as well as the people working in it and the individuals it exists to serve; and it isn’t going to go away.”*

This best practice guidance does not detract from the strength of face-to-face professional support; social media communication is not a replacement. However, it can empower and enable

young people to choose how to access information, at a time and place that is convenient to them, at a time when a lot of control in their lives is taken away from them simply because of their diagnosis.

### Youth and digital media

Innovative research from the USA in mid 1990 talked about young people’s experiences online [Turkle: 1995]. The earliest research on youth and mobile phones was conducted around 2000; this showed that European young people were relatively early users of mobile phones and texting from around the 1990s. Young people from Japan quickly followed in the late 1990s. However, terms like digital and social media are relatively new, the latter was used initially in 2005, reflecting the growth of multiple uses of the internet [Ito: 2010]. However, before then young people were already using applications, for example instant messaging and taking pictures and uploading them online. As the technology has developed, so too has the risk agenda.

The mid-2000s, witnessed mobile phones being enabled for internet access, and discussions of increased risk for young people [and children] emerged in particular relation to young people being able to access the internet with reduced parental oversight. Five years later, the inception of smart phones among young people led to greater capabilities and opportunities for young people to benefit from the use of such technology, but also led to new concerns about the importance of how such use can be safe [Haddon:2015].

This is an argument that is frequently used by health professionals who are concerned about the use of social media within health settings, in particular using such tools to communicate with young people. This paper aims to overcome such concerns and provide evidence of the benefits of such tools for communication, with examples of good as well as importantly, safe practice.

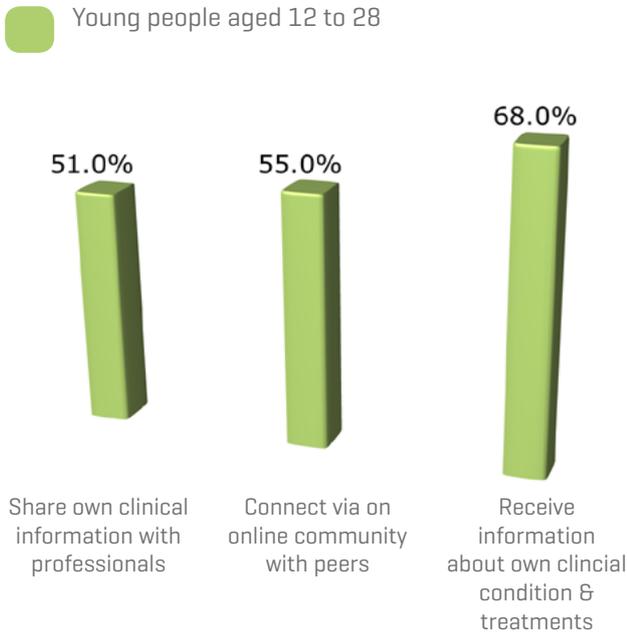




## Research in the teenage and young adult community

Digital communication is changing the way patients learn about and manage their health conditions; in 2013 Mike Groszmann with teenage and young adult multi-disciplinary team colleagues, launched research into digital communication. Respondents were aged 12 to 28, and were asked what communication they would like to receive digitally:

### Young people said they would like to receive digital communication to



Young people respondents said email was the preferred method of communication, followed by text. Digital communication was described as essential to their life by 70% of the young people, and 91% said they use a smartphone to access the internet more than once a day. The research concluded that young people want more online resources and there is an opportunity to respond to this evolving digital need.

CLIC Sargent's report Coping with cancer [2014] asked young people their views on accessing information and being emotionally resilient. The report findings concurred with previous research, that social media is a growing phenomenon; the ability to remain anonymous and ease of accessibility were key factors for the young people.

### Overwhelmingly 96% of young people with cancer said they would use the internet to access information & advice



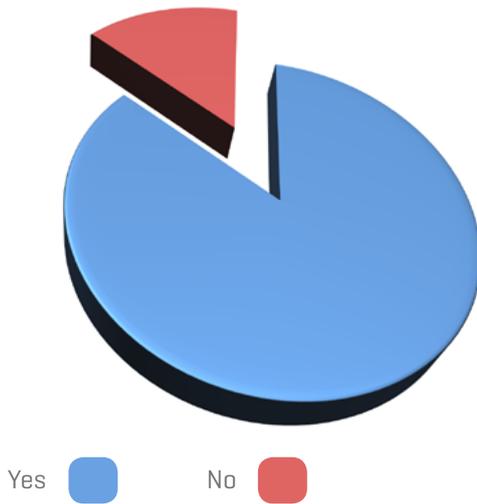
Young people highlighted the importance of connecting with other young people who had cancer with 78% of the respondents highlighting the importance of social media and forums to share their experiences and advice. Young people voiced disadvantages of social media including feeling overwhelmed and lack of clarity due to the sheer amount of information available, finding trustworthy age- appropriate, specific information was a challenge and looking at data such as cancer survival statistics felt uncomfortable.



## Research with TYAC members, October 2015

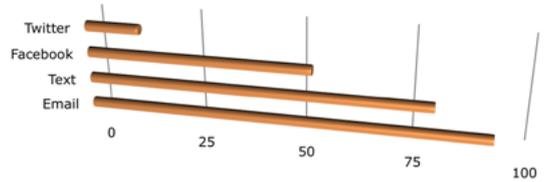
We conducted a survey of TYAC members, in October 2015. With only 20 respondents this data must be considered with caution. Nearly all of the respondents to the survey were nurses.

### Do you use digital communication with TYA's



Not having the right technology was the reason for 75% of those who did not use digital communication with TYAs. This was followed equally by risk of safeguarding issues, a preference for face to face contact, and it being against work policy. They all used telephone as the main method of communication with young people, additionally around 30% also used letters.

Of the 85% who used digital communication, email was by far the preferred tool:



Of those who used digital media, 80% said information giving was the key purpose. This was followed by 60% who used it to let young people know about appointments, 53% communicated about social events for young people and 27% used it for online peer support. Respondents shared that social media means a quicker response from young people; it is an incredibly convenient method of communicating for the professional and young person. It also promotes peer support and the sharing of information. Interestingly, none of the respondents had experienced any concerns themselves from using digital communication with young people.



## Best practice examples including tips into how to overcome challenges

### *Setting up a Facebook group in a hospital*

Gavin Maynard-Wyatt, Clinical TYA Lead Cancer Nurse, shares his experience of setting up one of the first Facebook groups for teenagers and young adults in hospital:

“The first challenge was to find out from our IT department if Facebook could be accessed via a work computer. Once I had sent them my Job Description which showed that my work focus was supporting young people, accessing Facebook from a work computer turned out not to be a problem at all.

Approval for the idea was sought from the clinical governance committee who were very enthusiastic about the idea of a Facebook page for event organisation and peer support. They requested an operational policy [example from The Marsden in appendix 2] to highlight how the page would be set up, managed and monitored. This was passed at the next clinical governance meeting.

Next step was to write a disclaimer [included within operational policy] for the TYAs to sign before having access to the Facebook page. This was sent to our communications department for slight amendments. We were then ready to set up the page. This was done with the help of a member of staff at the Teenage Cancer Trust.

Once the page was set up, we were ready to start offering the page to our TYAs. No issues have arisen of concern or safeguarding with the page. The only pitfall is that our policy includes checking the page daily. The staff team communicate with each other to say when we are on leave to allow others to check more frequently. We have also set up a check system on Facebook so each checker can monitor it”.

## How social media can reduce DNAs

### *Living it UP*

This is a medical practice in Moray, Scotland [living it up.org.uk] who use texts and reminders to their patients, who are not just young people but all clients. As a result they have seen reduced ‘did not attend’ rates and they are now using such communication tools to promote healthy living campaigns.

## How social media can provide information and encourage peer support

### *Beatson Teenage Cancer Trust Facebook group*

This group has a clear, succinct policy which sets out the practice in a way that safeguards both the professionals and young people. The clear purpose is to provide social events to TYAs with cancer that are being treated within the region. The site is overseen by two members of staff. Only patients that are known will be accepted as ‘friends’ to the group; it will not include families or friends. There is a consent form which young people sign, and if under 16 it also requires the signature of a parent/guardian. This is accompanied by terms and conditions which outline behaviour and disclaimers.

## How social media can enable peer support

### *CLIC Sargent Online community*

This online community is for 16 to 24-year-olds who have, or have had, cancer to enable them to share experiences, make friends, find useful information and support each other through difficult times. In response to feedback from young people an app was launched in 2015. Young people have recently taken part in ‘ask the expert sessions’ about sex and fertility, and friendships.

Young people have told us they can take part in the community and ‘ask the expert’ sessions anonymously, which means it is a safe space to talk about very personal, sensitive topics. The community has balanced safeguards with simple steps including young people signing up to become members, with verification of age. Young people helped to design the community including the terms and conditions for being a member. A community manager oversees the community in a role of encouraging peer discussion and ensuring the tone and content is age-appropriate.



# Internet safety

## Safeguarding

The TYAC survey on the use of social media in TYA Cancer care, whilst limited in reach, highlighted one of the key blocks to social media being used to its fullest potential: concerns about safeguarding young people. This reflects current media stories about issues such as trolling, and how negative an impact this can have on young people.

*Trolling is the sending of menacing or upsetting messages on social networks, chatrooms or online games.* [NSPCC Keeping safe online [www.nspcc.org.uk](http://www.nspcc.org.uk)]

Safeguarding remains a priority whether in virtual or 'real' life. In all our work, including social media, safeguarding the wellbeing of young people is paramount. Bullying, harassment and adverse behaviour to young people similarly exists out of the virtual world of social media and we set safeguards in place to limit the risks of these. This paper sets out how to put similar safeguards in place for the virtual world of social media.

The following are best practice examples of how colleagues have ensured the safety and wellbeing of young people in communication via social media.

## Best practice tips for young people's safety

- Ask the young person how they prefer to be contacted. This gives them control and empowers them to lead the professional relationship.
- Have a clear social media statement you share openly with young people [appendix 1 – The Beatson best practice example].
- Encourage young people to really think before they post comments on an online community or shared network, especially about personal information or feelings. Use phrases like "only post something that you would say to someone you didn't know face-to-face".

UK Safer Internet Charity provides five tips for young people to stay safe using social media:

1. **Protect your online reputation:** use the tools provided by online services to manage your digital footprints and 'think before you post.' Content posted online can last forever and could be shared publicly by anyone.
2. **Know where to find help:** understand how to report to service providers and use blocking and deleting tools. If something happens that upsets you online, it's never too late to tell someone.
3. **Don't give in to pressure:** if you lose your inhibitions you've lost control; once you've pressed send you can't take it back.
4. **Respect the law:** use reliable services and know how to legally access the music, film and TV you want.
5. **Acknowledge your sources:** use trustworthy content and remember to give credit when using other people's work/ideas.

They also have some great online guides on how to stay safe on Facebook, Snapchat and Twitter, for more information go to [www.saferinternet.org.uk](http://www.saferinternet.org.uk).

Best practice tips for ensuring staff use social media safely:

- Read your hospital or employer's social media policy.
- Read your profession's social media policy or guidelines.
- Review your own security settings on your own social media accounts.
- Record contacts with young people made via social media on your organisation's recording systems, as you would have if it was a face-to-face contact.
- Ensure you have the agreement of your manager to use social media in communication with young people who are service users. It may be helpful to explain the pros and cons with them, and share this best practice guide too.
- Do not use your personal smart phone or tablet to communicate; it is important to maintain professional boundaries [appendix 3 example policy on SMS].
- If you use a profile photograph be aware of who is in the picture, should they be for work purposes? What does the photograph or your 'behaviour' in the photograph portray?
- Maintain your professional communication skills; avoid the use of slang in texts for example. It isn't cool!
- Having a social media policy or agreement for use with staff members which sets out what is and isn't accepted behaviour and usage of social media.
- Young people often use emoticons such as kisses or smiley faces in emails or texts. It does not necessarily follow that you should too; using kisses oversteps the professional boundary. However for some an emoticon such as a smiley face can offer a softening of a communication. It depends on your profession. If in doubt check with your line manager and professional standards. We recommend an open conversation with the young person to avoid confusion.

## So how do young people wish to communicate?

Young People are clear that in their communications with healthcare professionals for information, to arrange appointments or things like quick questions their preferred method of communication is email. Their next preferred method is text.

To link with peers and talk anonymously their preferred method of communication is an online community. For more in-depth listening support their preferred method continues to be face-to-face skilled support from a professional they know and trust.



### USEFUL LINKS

[www.nhsemployers.org/socialmedia](http://www.nhsemployers.org/socialmedia)

[www.nmc.org.uk/standards/guidance/social-media-guidance](http://www.nmc.org.uk/standards/guidance/social-media-guidance)

[www.gmc-uk.org/guidance/28572.asp](http://www.gmc-uk.org/guidance/28572.asp)

Multiple documents and discussions for Doctors on using social media

[www.nhsemployers.org/publications](http://www.nhsemployers.org/publications)

Quick guide for new starters. New to the NHS? Your guide to using social media in the NHS, November 2014.



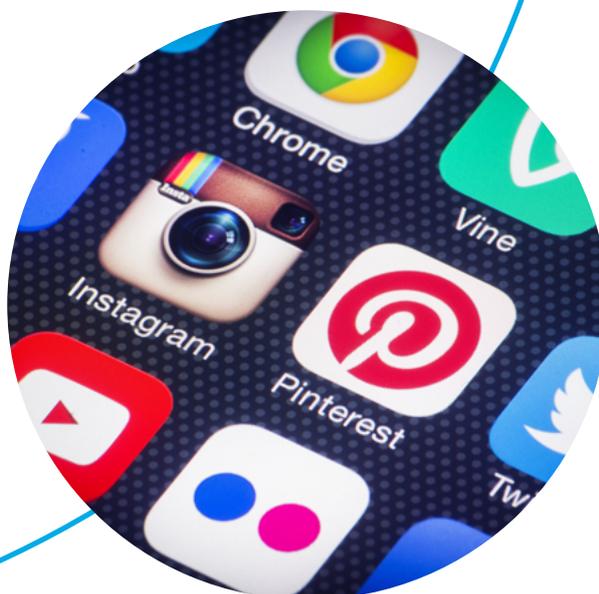
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McCrae, J. [2015] On the brink of some thing special. NHS providers.

Turkle, S. [1995] Life on the Screen: Identity in the Age of the Internet. Simon & Schuster; England



# APPENDICES

## Appendix I:

Used by The Beatson, West of Scotland Cancer Centre in welcome packs for young people

### Teenage and Young Adult Cancer Service Social Networking

All the staff on the ward are here to look after you and we understand that you will get to know some of us very well. It is important that all patients and families are treated equally and professionally, so staff are not allowed to be in contact with you through Facebook, Twitter, Bebo or any other social networking site. Staff are also not allowed to be in contact with you through any other method such as personal phone calls, text or emails when they are not at work or when they have left to work somewhere else.

Thank you for your understanding on this matter. If you wish to discuss this further please speak to your Clinical Nurse Specialist or the ward manager.

Teenage and Young Adult Cancer Team

## Appendix II: TEENAGE AND YOUNG ADULT (TYA) FACEBOOK GROUP OPERATIONAL POLICY – The Marsden

### Summary

This policy describes the use of the TYA Facebook Group, the reasoning behind it, membership, access arrangements, and the approach to security and privacy. It also outlines the kinds of interactions which are encouraged, and the role of Royal Marsden staff members in administering and moderating the TYA Facebook Group. Guidelines on appropriate use and consent forms for members are appended.

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Appendix II	Consent Form for Membership of TYA Facebook Group

### 1. Background

1.1 Teenagers and young adults who have been treated for cancer benefit enormously from a variety of forums and media in which they can share feelings and experiences with their peers and provide mutual support to each other through all stages of treatment and its aftermath. The development of popular social networking sites such as Facebook provides an opportunity for such peer support. The TYA Facebook Group will allow young people, who may be physically remote from each other, to maintain and benefit from ongoing communication at a time when they most require it.

### 2. Definitions

2.1 A Facebook Group: refers to a “closed space for small groups of people to communicate about shared interests”. When you create a group, you can decide whether it is open to all or whether it requires administrator approval to join, and whether to keep it private or by invitation only.

2.2 Secret Group: refers to a Facebook group with the highest levels of privacy. It cannot be found in searches, and non-members cannot see anything about the group, including its name and member list. The TYA Facebook Group will be at this level of security.

2.3 Member: refers to a teenager or young adult who is part of the TYA Facebook Group.

2.4 Teenagers and young adults (TYA): This policy limits membership of the TYA Facebook Group to TYA aged between 16 and 24 years and 364 days who received treatment for cancer at The Royal Marsden since 1st March 2014.

### 3. Purpose and Ethos of the TYA Facebook Group

3.1 The TYA Facebook Group is intended for two main uses: -

- networking for teenagers and young adults (this is the primary purpose)
- posting of information on events and activities for young people by the TCT Youth Support Worker.

3.2 Members should be able to use the TYA Facebook Group as a way of talking to others who have been through similar experiences and challenges. The TYA Facebook Group should not be used to post messages that are abusive, inappropriate or harmful to others, or complaints about services or staff or which otherwise breach the guidelines [Appendix I]. Requests for medical information from moderators about clinical diagnosis, treatment, prognosis, etc will not be allowed and will be removed if posted and the individual contacted to explain the reasons for this. Individuals with such queries will be directed to appropriate medical or other resources. Individuals who appear in need of urgent support may be contacted to provide assistance.

3.3 The site is not intended as a forum for communicating acute distress or seeking professional assistance, and prospective members will be informed of this. However, in certain circumstances where individuals may be at risk or in distress, moderators may intervene and contact individuals to offer assistance [See Appendix I & II]. In hours moderators will have access to a spreadsheet of current users and their contact details, these can be used in conjunction the electronic patient records to identify & contact users if needed. Out of Hours the spreadsheet and a Trust laptop will enable the facilitator to do the same.

3.4 The site will be moderated by Royal Marsden staff, but their contributions and interventions should be limited, and largely anonymous, to reinforce the sense that the site is for TYA rather than staff.

#### 4. Membership

4.1 Membership will be open to young people between the ages of 16 and 24 years and 364 days who were diagnosed and treated for cancer at The Royal Marsden from 1st March 2014. Membership will be valid for two years.

4.2 Membership will not be open to young people who have been treated at other hospitals, nor to family, friends, volunteers or staff at The Royal Marsden. However, some Royal Marsden staff will be designated as anonymous moderators, rather than members, and will be able to make contributions or posts in this role.

4.3 Membership will be conditional upon agreement to abide by clear guidelines [Appendix I], and may be ended if these are breached, at the discretion of moderators.

4.4 Membership will be monitored by the TCT Youth support Worker and TCT Nurse Consultant for TYA on the first Tuesday of the month to identify people who have reached the time limit and enable them to be signposted to other appropriate resources. The TYA Facebook Group is expected to be a valuable source of support for young people, so the process of reviewing membership will require sensitivity and flexibility to ensure that other sources of support are in place, and that time is allowed for the member to access these.

#### 5. The role and responsibilities of moderators

5.1 The moderators of the TYA Facebook Group will be TCT Nurse Consultant for Adolescents & Young Adults [weekends, bank holidays and in the absence of the TCT youth support worker], the TCT Youth Support worker [Monday to Friday] The TCTU ward sister will cover weekends and bank holidays in the absence of the TCT Nurse Consultant. The page will be moderated once a day.

5.2 Moderators will not use their own Facebook identity to manage the Group. Instead, they will log in using a generic Facebook account with the name tya Marsden. This ensures that they do not take part as identifiable individuals in the interactions of the members. In order to avoid potential confusion

between this and their own account, they must remember to log out when they are finished.

5.3 A moderator rota will be established and maintained by the TCT Support Worker and will be available on the TCTU shared drive.

5.4 Their role is to: -

- review and action requests for membership of the TYA Facebook Group and verify the identity and eligibility of the potential member
- visit the TYA Facebook Group daily (including weekends and Bank Holidays) and review the content to ensure that the guidelines are not breached, and take appropriate action if they are
- remove inappropriate posts and explain the reasoning behind this
- review the content and respond to posts that may indicate that individuals are in acute distress or in danger of physical or psychological harm and take appropriate action
- post information about upcoming events and opportunities and respond to any queries about these
- review the guidelines and information/safety advice for new and existing members from time to time to ensure they are up to date and reflect current needs
- participate in moderator discussions and meetings to review the working of the site and maintain consistent practice.

5.5 Their responsibility is to undergo relevant training so that they understand:

- their roles and responsibilities
- online privacy, safety and security
- the legal responsibilities of moderators
- how to respond to members at risk
- internet safety in general
- use of Facebook and potential risk issues including identity theft, password security, and privacy settings
- cyber-bullying and safety on the internet for young people including child protection.

Training has been jointly run by The Royal Marsden and Online Youth Outreach <http://www.katiebacon.co.uk/consultancy-training>

#### 6. Security, Privacy, and Safety Issues for TYA Facebook Group members

6.1 The TYA Facebook Group will be a secret group - it cannot be found in searches or be viewed by non-members. The name of the TYA Facebook Group will not display on the profiles or timelines of members. Membership is by invitation only.

6.2 Teenagers and young adults will be asked to use a Facebook account with an email address that is unique to them and not shared with, for example, a parent or other person, and to respect the privacy of others who post on the site.

6.3 Members of the TYA Facebook Group will be provided with written information [Appendix II] about internet safety, privacy and security, and encouraged to follow this. The advice will be updated as new issues arise and safety measures are developed.

## Appendix I: TYA Facebook Group information & guidelines for young people

This leaflet is to let you know about The Royal Marsden TYA Facebook Group. The TYA Facebook Group is for young people aged between 16 and 24 years who are patients at The Royal Marsden.

The main aim of the group is to enable young people being treated at The Royal Marsden to contact other young people who are in a similar situation.

It will also enable the Teenage and Young Adult service at The Royal Marsden to post notices about upcoming events and activities.

The TYA Facebook Group will function slightly differently from other Facebook groups and it will have some things that you will need to keep in mind.

Here's a summary of how it will work.

### It's a private Facebook Group

It is completely invisible to non-members of the group. No one will be able to find it via an internet search and only members of the group can see what is posted inside it. Even your closest Facebook friends won't be able to see what you say inside the group [unless of course they are also members].

Everything inside the group though is open to all. The group's members will be able to see who else is a member and any conversations inside the group will be visible to everyone.

### Who can be a member?

Membership is only for young people aged between 16 and 24 years who are patients at The Royal Marsden. Membership is managed by a small number of Royal Marsden staff. This means that the following people cannot be members.

- Your regular Facebook friends and members of your family.
- Members of the general public.
- Young people who have been treated at cancer hospitals other than The Royal Marsden (e.g. young people from other hospitals that you might have met at regional/national events).
- Nurses, doctors, social workers and other staff at the Royal Marsden [except the moderators].
- Patients more than two years after completion of treatment at RMH

### Who are the moderators?

A small group of staff [about 4 people] at The Royal Marsden will have access to TYA Facebook Group. This is because they need to monitor the group to make sure that everything is running smoothly and to post occasional events and notices.

### Are there things that cannot be posted in the TYA Facebook Group?

To ensure the TYA Facebook Group is a positive experience for its members there are some terms and conditions which are attached. You need to read and agree these, and sign and return the consent form to us.

### Will the group be moderated?

Yes, the TYA Facebook Group will be accessed once a day [including weekends and bank holidays] by a moderator to make sure that everything is running smoothly. They will keep their comments to a minimum. The moderators are a small group of professionals who work within the TYA service at The Royal Marsden but they will not use their real names or Facebook names.

Moderators will ensure posts are appropriate. They may remove inappropriate or unhelpful comments. They may also arrange for you to be contacted if they feel that you are in urgent need of assistance.

### What if I need help urgently?

The TYA Facebook Group is not to be used to seek medical help if are unwell please call the hospital switchboard on 020 8642 6011 or dial 999

If you are upset or distressed or need help for other mental health issues you can seek help as listed below. If you are concerned about a friend please encourage the person to contact Samaritans helpline below:

Monday-Friday 9am-5pm you can contact the paediatric and psychological support team for advice on 020 8661 3676/3006.

Contact your GP urgently as an emergency, out of hours you will be directed to the out of hours number

Go to A&E and ask for the duty psychiatrist

Samaritans 08457 90 90 90 or <http://www.samaritans.org/>

Facebook users can submit reports of potentially suicidal content to the website by clicking on a link on the facebook help page that allows them to record the name and details of the person they are concerned about.

Facebook will immediately alert the police if the person is judged to be at imminent risk and pass on all alerts to the Samaritans

### What if I want to leave the group?

You can leave the Group at any time by changing your settings in Facebook.

### How long can I remain a member of the group?

Usually, you can be a member of the group until two years after the end of your treatment. You will then be contacted about ending your membership. However, we will always ask you if you need any assistance, and we will put you in touch with other services that may assist you if you are having difficulties.

### How do I join?

Because this is a secret group, you have to be invited to join by either a member or via an invitation from the TYA Facebook Group alias Billy's mates.

When you accept the invitation to join, one of the moderators will check that you are eligible and that you have returned a consent form. Once that process has been completed your membership will be confirmed.

Once you are a member we encourage you to invite any other Royal Marsden patients with whom you are Facebook friends so that they can join too.

### Courtesy on the TYA Facebook Group

To become a member of the TYA Facebook Group, you must agree to abide by these guidelines, and sign the attached consent form to confirm that you do ticking the appropriate boxes.

### Appropriate Postings

Please keep contributions constructive, relevant and polite.

You should not use the TYA Facebook Group to make complaints about professionals, individual hospitals or treatment centres. You should use the relevant hospital and other complaints procedures for this.

### Communicating with others in the Group

Be polite: please ensure that your contributions are respectful of others. We will remove contributions that are unlawful, harassing, defamatory, abusive, threatening, obscene, sexually suggestive, racist, homophobic or sexist or that incite or promote hatred of any of individual.

*Writing in capitals:* do not write in capital letters – on the internet this is regarded as “shouting” and many people are offended by it.

*Abusive language:* comments containing swearing will be removed.

*English:* all comments on the website must be made in English. Comments in other languages will be removed.

### Naming people and privacy

Whether you are speaking for yourself or on behalf of another person – do not name the individuals you are talking about. If you are making a comment about another person please use terms of “my boyfriend”, “another patient at the Royal Marsden” and so on to protect their privacy.

You should avoid comments that are damaging to the reputation of another person or organisation. Avoid naming any NHS staff that may have treated you or someone on whose behalf you are commenting. If a person could be identified by where in the hospital they work, you should avoid mentioning that too.

### Complaining about another person's comment

If you think that someone's contribution to the TYA Facebook Group is inappropriate please use the controls in Facebook for hiding comments as spam, reporting them, blocking the other user or giving them feedback. You can also email [tya.groupmod@rmh.nhs.uk](mailto:tya.groupmod@rmh.nhs.uk) or call the Teenage Cancer Trust Unit. Reporting a comment will not automatically remove it but it will be dealt with as soon as possible.

### Health, advice, medical products and commercial activity

Asking for and giving specific medical advice is not permitted and will be removed. Comments deemed to be advertising a product or service will be removed. We may remove references to specific medical products or medicines if the context is not appropriate.

### Legal issues, criminal activity or negligence

Accusations of specific criminal activity will be removed. If you believe that criminal activity is or has taken place at any hospital please contact the police or the hospital directly.

### Copyright

Ensure that you own the copyright to any material you put on the site – especially if you have copied it from another source. If we are in doubt about the ownership of content we will remove it from the site.

### Actions we may take

A breach of any of our rules can lead to your comment or post being removed. Repeated or serious breaches of our rules may lead to the termination of your membership of the TYA Facebook Group.

### Safety and security on the internet

A Guide to Facebook Security for Young Adults, Parents, and Educators  
Linda McCarthy, Keith Watson, and Denise Weldon-Siviy  
[www.facebook.com/safety/attachment/Guide%20to%20Facebook%20Security.pdf](http://www.facebook.com/safety/attachment/Guide%20to%20Facebook%20Security.pdf)

Think u Know – A Guide to Safe Surfing for teenagers  
[www.thinkuknow.co.uk/](http://www.thinkuknow.co.uk/)

The Rough Guide to Online Safety  
[www.getsafeonline.org/themes/site\\_themes/getsafeonline/pdf/GetSafeOnline\\_RoughGuide.pdf](http://www.getsafeonline.org/themes/site_themes/getsafeonline/pdf/GetSafeOnline_RoughGuide.pdf)

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## Appendix II: Consent Form: Membership of the Royal Marsden Teenage and Young Adult Facebook Group

The purpose of this document is to confirm that you give your consent to become a member of the Teenage and Young Adult Facebook Group.

To become a member, you must sign and return this document.

Please initial the appropriate boxes

I have been provided with information about or internet links to Facebook safety and security and advised to read and follow them

I understand that my taking part is voluntary; I can leave the Group at any time and I will not be asked any questions about why I no longer want to be involved.

I understand my personal details will not be revealed to people outside the TYA Facebook Group

I understand that I will not be allowed to discuss my clinical care with members of this group

I have read the guidelines provided to me about membership of the TYA Facebook Group, and have agreed to abide by them and to respect the privacy of members. I understand that breaches of these guidelines may lead to the ending of my membership of the TYA Facebook Group

I understand that my membership of the TYA Facebook Group will cease two years from the end of my active treatment at The Royal Marsden [e.g. chemotherapy, radiotherapy or clinical trial].

For emergency contact details only please provide us with the following details

-----  
Facebook name

-----  
Mobile number

-----  
e-mail address

-----  
Name                      Electronic Signature\*      Date

Please now return this form to one of the moderators:

Contact address for moderators – [tya.groupmod@rmh.nhs.uk](mailto:tya.groupmod@rmh.nhs.uk).

\*You may type your signature here and return the form. We may contact you to verify that this electronic signature is yours.

## Appendix III: The use of short messaging service [SMS] messaging services with teenage and young adult [TYA] patients – The Marsden

### 1.0 Introduction

1.1 Technology is a central part of the teenage and young adult's lives recent research shows that people under the age of 25yr olds are more likely to communicate by text [SMS] than any other form of communication [Lenhart et al 2010]. The use of SMS in healthcare has vastly increased in recent years [Krishna 2009] and when used with good clinical practice can improve quality of patient care and can deliver for healthcare information to TYA in an efficient, organized, and effective manner [Hassan et al 2010].

1.2 The three most recognised ways to use SMS with TYA patients [RCN 2006] are:

- a. Simple. This is initiated by the service provider and is usually a reminder about an appointment, or to make contact with a TYA patient where other means of communication i.e. telephone call or letter have failed
- b. Automated. A service user initiates a request for information and receives a programmed response
- c. Personal response. A service user asks a question about their person health or care to a specific health care professional who responds accordingly.

### 2.0 Aim of policy

2.1 This policy sets out the circumstances in which teenage and young adult patients [16-24 years old] may be contacted by SMS and the procedures that must be followed when using this method of communication.

### 3.0 Use of SMS

3.1 SMS will be used to communicate for the following reasons

- Arrange appointments.
- Remind the patient of appointments.
- Request the patient to contact the Trust.
- Provide brief non-sensitive information to patients.

### 4.0 Patient eligibility for SMS service

4.1 The SMS will only be offered to patients thought to benefit from such a service i.e. TYA patients who live alone without the support of carers/family; patients who are deaf or hard of hearing; patients who are hard to engage with by other means of communication.

4.2 Any member of the patient's healthcare team can suggest a patient be offered the SMS

4.3 Assessment and inclusion of patients in this service will be discussed and agreed by the TYA multidisciplinary team meeting or the TCT Nurse Consultant for Adolescents and Young Adults.

## 5.0 Patient information and consent

5.1 Patients who are the recipients of the SMS service must consent to SMS being used to communicate with them before initiating the service. This consent can be verbal but must be recorded on the patient's EPR. The patient information leaflet (appendix 1) will be given to patients explaining the use of the SMS service.

5.2 Messages from RMH staff must only be sent to the mobile 'phone number given by the patient at the time of consent.

## 6.0 Governance

6.1 In accordance with professional codes of practice and governance process within the Royal Marsden NHS Foundation Trust [Confidentiality Code of Practice and Data Protection Policy and Procedure 2008 (277)] healthcare professionals must treat all information created in the SMS as confidential and use it only for the purpose for which it was intended.

6.2 SMS must never be used for sensitive personal information such as test results or discharge summaries.

6.3 Professional reasoning and judgement must be used when responding to text messages based on the information received, such information must be regarded as patient contact

6.4 All messages should be documented, and include the following information: text; telephone number, time, response, action taken, dated and signed in accordance with professional codes of practice and the Data protection Act [1998].

6.5 A record of the text message sent and received from the patient must be annotated onto the patients electronic record in accordance with Clinical Documentation and Record Keeping Policy [1635]

6.5 All received messages must be deleted from the mobile 'phone after documentation to ensure confidentiality

## 7.0 Operational

7.1 Only mobile 'phones provided to healthcare professional by RMH can be used to text TYA patients, all such 'phones must have a password known only to the user of that 'phone. When not in use the 'phone must be kept in a locked drawer/cupboard.

7.2 In the event of theft/loss of the mobile' phone the theft must be reported to the police and telephone company as soon as the loss/theft is known and the procedures outlined in incident reporting policy are to be followed as soon as possible.

7.3 Text language must not be used in sending messages on any subject to TYA patients

7.4 Messages must be read through before sending them to ensure the message is clear and can be understood and that spelling and grammar are correct.

7.5 Wherever possible the SMS service available to nhs.net mail users must be used as a safe and secure method of using SMS. Instructions on how to do this can be found on the nhsmail

[http://elftintranet/it\\_support\\_and\\_services/how\\_to\\_set\\_up\\_an\\_nhs\\_mail\\_account.asp](http://elftintranet/it_support_and_services/how_to_set_up_an_nhs_mail_account.asp).

## 8.0 References

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Krishna S et al [2009]. Healthcare via cell phones: a systematic review. Telemedicine Journal E Health.15(3) 231-40.

Royal College of Nursing [2006] Use of Text Messaging Services – Guidance for Nurses working with young people and children. Royal College of Nursing. London.

## 9.0 Author

9.1 Louise Soanes [V1: 22nd July 2010]

## Appendix I:

### Patient information on the TYA short messaging service (texting)

To help communicate with you more effectively

Healthcare staff working at the Royal Marsden NHS Foundation Trust will only text you on the following mobile 'phone *[number of the mobile 'phone given by the patient]*

The mobile 'phone number for the healthcare staff working at the Royal Marsden NHS Foundation Trust who provide a SMS service are *[number of the mobile 'phone[s] given to the patients]*

This mobile 'phone can be used to ask questions relating to your health care needs during the hours of *[time]* and *[time]* , on *[days of the week]*.

The expected response time will be within 1 hour of the text

If there is no response within an hour please contact *[alternative telephone number]*

In case of a medical emergency DO NOT use the SMS service. Call 999 or contact *[alternative telephone number]*

All information given and received on this service will be held in confidence, a record of the texts will be transcribe to your medical records

Abuse of the service will not be tolerated, any abuses will result in the service being withdrawn.



## About TYAC

Teenagers and Young Adults with Cancer is a registered charity and the UK's only membership body open to all professionals involved in the care of teenagers and young adults with cancer. By providing information on best practice and new developments, training and support to our members, we aim to improve the quality of life and likelihood of survival for young people with cancer.

Our vision is that all teenagers and young adults with cancer in the UK receive the best possible treatment and support.

For more information on membership

**Visit:** [www.tyac.org.uk](http://www.tyac.org.uk)

**Email:** [info@tyac.org.uk](mailto:info@tyac.org.uk)

**Call:** 0115 9033 033

Follow us on Twitter: @TYACancerPro

Join us on LinkedIn: Teenagers and Young Adults with Cancer [TYAC] Professionals

Teenagers and Young Adults with Cancer [TYAC] is supported by:



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**Teenagers and Young Adults with Cancer**

*Uniting professionals. Improving practice*

### Disclaimer

Teenagers and Young Adults with Cancer [TYAC] does not sponsor or indemnify the treatment/best practice guidance detailed herein. These recommendations are provided by the TYAC service development group to inform and for use at the sole discretion of the social care/allied health care/health care professionals who retain professional responsibility for their actions and therapeutic interventions. Any recommendations herein are based on current best-practice with supporting evidence, where any such evidence exists.