The Internet and Clinical Neuropsychology

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The internet is the single largest and most diverse resource available to clinical neuropsychologists and remains a powerful ally for any patient focused practitioner. It is useful not only because it provides convenient access to a vast array of clinical and scientific information, but also because it allows disparate individuals to widen the informal networks that provide the bedrock of mutual co-operation and education that characterises contemporary clinical science.

This silver lining does not however, come without an accompanying cloud and as with any clinical tool, there are practical and ethical issues that have to be addressed. Whilst no clinician would dream of using a novel practice without fully understanding its implications it is not unusual for even the most accomplished of clinical scientists to understand only enough of the internet to facilitate its use without being able to address these issues. This inevitably leads at best to wasted time and frustration, and at worst to serious implications for the welfare of patients (Alejandro et al, 2000).

This chapter aims to provide practical advice so time on the internet can be used effectively, whilst giving an outline of the additional ethical considerations that internet communication presents.

E-mail communication and etiquette

E-mail has always been the *lingua franca* of internet communication by virtue of its ubiquitous nature and flexibility. The utility of a system that allows electronic messages to be delivered to an individual, usually within minutes and regardless of their physical location, would seem to be self evident.

As Smith and Senior (2001) have noted, e-mail is becoming the preferred method of communication for the psychologist, and clinical neuropsychologists will undoubtedly find this facility as useful, if not more so, than any other e-mail user. For this reason it is important that clinicians should be fully aware of the facilities, pitfalls and customs that accompany e-mail communication.

One-to-one email communication.
As with any sort of communication, messages must be appropriate to their recipient and so content and style may differ accordingly. However, there are several ways of using the medium to its best advantage for the benefit of both parties.

Write clearly and provide context. Whilst an email may be perfectly understandable in the context of an ongoing dialogue, when read some months or even weeks later it may make

little sense. This may not be such an issue for informal communication, but exchanges concerning issues of importance may be referred back to as is frequently the case in clinical settings.

One simple way of doing this is to use context quoting, where the *relevant* section of the received e-mail is quoted with the response added below, like thus:

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> I still haven't found the amnesia paper I was after.
Not too worry, I found a copy and will post it to you.
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This allows your reply to be concise whilst maintaining context and avoiding the unnecessary bulk of including the whole of the previous email.

Use the lowest common denominator. Plain text is preferable to any form of embellishment that an email program may provide such as sending HTML mail (creating and sending email as web pages). Everyone on the internet can read plain text email, not everyone may be able to read any additional features that may be added. Even if you know that the person you are writing to can read your special format of email, this might prevent someone else from reading it if it gets forwarded on as is often the case in the team environments that clinical neuropsychologists commonly work in.

Attachments must be appropriate. Whilst many pages of plain text will still only take seconds to download on the slowest internet connection, attaching a file can greatly increase download time. It is good practice to ask whether a person wishes to receive an attachment if it exceeds 500k in size and when sending an attachment state its size and type clearly, as this may not always be obvious to the recipient (e.g. "the attached paper is a 240k Microsoft Word 97 file").

Remember, email is not written speech. Due to the nature of text based communication many of the subtleties of face to face communication are easily lost, leading to a message being misinterpreted. Particular caution must be taken when using sarcasm, humour or ambiguous statements. Similarly, short functional replies may be interpreted as irritable. Sentences or phrases can be emphasised or softened by the use of punctuation such as asterisks ("I really must *stress* this point") or by using emoticons or 'smileys' to indicate the emotional context of a statement. Excessive use of emoticons is considered a little gauche and most people stick to simplified versions such as :) to indicate positive emotion, for example:

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I really enjoyed your talk :)
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or :(to indicate a negative emotion

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That's the third time this week :(
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One-to-many email communication.
Discussion lists, where email is used to continue an ongoing dialogue with a group of people, can be a source of practical help, support and inspiration as well as a distraction and annoyance. One enquiring email to a group of similarly focused professionals can be worth many hours searching through databases or on the phone, and such lists may also serve as a source of news and announcements and as a way of forming informal associations that can lead to valuable collaborations. Internet discussion lists are however, notorious for bringing

out the worst in people, not least because e-mail can so easily be misinterpreted, but also because it is often difficult to fathom the unwritten rules of the group without accidentally violating them.

Simple guidelines (colloquially called 'netiquette') have been formulated to facilitate group interaction in internet discussion groups and include the points covered in our discussion for one to one email communication, with a few additions and alterations.

<u>Attachments should not be sent to a discussion list</u>. Such lists may involve hundreds of subscribers, many of which will not appreciate having to receive a large file that may only be of interest to a minority. If you have a file you wish to disseminate, either ask who wishes to receive it and mail it to them personally, or if possible upload it to a web site and post the location so subscribers can download it at their leisure.

<u>Watch who you are replying to</u>. Additional recipients can be included in an email and by clicking the 'Reply' button you may inadvertently reply to them all. Similarly, if you wish to respond to a public email privately, make sure you are doing so and not accidentally mailing the whole list. Sending a personal email to a public list can be a cause of embarrassment, or in a clinical environment, a potential breach of confidentiality.

<u>Group emails should be of group benefit</u>. Discussion lists are measured by their signal to noise ratio. Lots of irrelevant chatter and 'content-free' contributions encourage an overall decrease in useful interaction and cause genuinely interested people to unsubscribe. That's not to say you necessarily always have to stick exactly to the list topic, but signal heavy content is usually much preferred. In some cases, the discussion list will be moderated so irrelevant messages will not reach the mailing list at all.

<u>Don't fan the flames</u>. 'Flaming' or the descent into vitriolic argument seem to be a fact of life on internet discussion lists. Clinical practice is, for most practitioners, a passionate interest and is likely to cause heated debate. Whilst it may seem a little patronising to remind competent professionals that other list members should be treated with respect, I have yet to find a discussion list where this has not happened at least once. Such heated exchanges are usually the result of a perceived but unintended slight, or when the participants do not realise that their exchange has gone beyond an informative debate of general interest into petty pedantry.

Using the Web
The world wide web has two major advantages for clinical neuropsychologists. Firstly that it allows the targeted retrieval of relevant clinical and scientific information and secondly that it allows information to be easily disseminated with the burden of acquisition placed upon the retriever. Documents, pictures, video or any other sort of digital information need only to be placed on the web, and their existence flagged so interested parties can access them, all without further intervention from the author.

Information retrieval
The most useful skill in searching the web for relevant information is not fishing out the gold but filtering out the rubbish. Search engines use entered keywords to identify pages that contain those words somewhere on the page, and hence the best strategy is often not to use words which best describe what you want to find, but to use words which are most likely to appear on pages containing the information you require. For example, searching the web using the keyword 'amnesia' brings up lots of irrelevant information as it is often used as a catchy name for everything from nightclubs to novels. However, a similar search using the keywords 'memory loss' returns lots of highly relevant references.

Humans are inevitably better at evaluating small amounts of information for relevancy than computers, so another useful technique is to use search engines to narrow the field or to give leads. In fields such a clinical neuropsychology where the sources of information may be limited, it is often the case that you may find yourself searching for pages that will then point you to the information you are eventually hoping to find. For example, if I wanted to find information about the notional conference "Neuropsychology and the Internet" entering these terms may produce a great deal of irrelevant results, either because there may be many pages containing these words which have nothing to do with the conference I wish to find, or because the conference web pages are either non-existent, or have not been catalogued by the search engines' databases. A preferred approach may be to search using the keywords "Neuropsychology Conferences" to find a page that lists conferences relevant to neuropsychologists (of which there are many) and look for a listing made by an ever reliable human.

Some search engines, and many online databases may allow searches to be made specific by searching for an exact phrase, or by using terms such as AND, OR and NOT. The use of such terms is out of the scope of this particular chapter but almost all facilities that allow such searches have online help and guides in their use. Users of longstanding electronic databases such as PsychINFO / PsychLIT or Medline / PubMed who recognise these terms may find that they can use exactly the same, or very similar syntax on many popular internet search engines.

It is worth noting that there is more to effective searching than being familiar with the tools. The internet can be thought of as a town. Whilst you may be perfectly competent at buying an items in a shop, it is your knowledge of the town that makes this ability useful. Similarly, spending time to overview the general internet resources available to clinical neuropsychologists is often useful for the same reason that general theoretical overviews are useful in any science. Whilst you may not have the information to hand, at least you know the best place to go and find it, saving you valuable time and frustration along the way.

Publishing information on the web.
Internet publishing can, in principal, simplify a great deal of the information distribution problem. Attendees can download notes from your talk, colleagues can retrieve minutes of meetings and important documentation such as ethics forms and other administrative templates. Whilst you can do the same without having to chase after the person with the keys to the right filing cabinet.

In practice, it is a lot more difficult, largely because the easy to use click-and-go tools are not yet available for web publishing as they are for web searching. To publish effectively on the web you either need to put some time and effort into learning the necessary steps, or if working in a suitable institution, have the support of suitably skilled computer or internet technicians.

It is pointless trying to outline all the necessary steps here, both because they will vary wildly depending on the web page hosting arrangements available (institutions own / commercial services / free services) and because high quality easy to understand guides are regularly published in internet magazines and provided by web hosting companies, who often have support lines to aid in technical issues.

As with most technology issues, the initial curve is the hardest to climb, and once completed, web publishing can be as painless as sending an email.

Some desirable features may or may not be available and it might be worth checking if you feel these might be necessary. Such features may include: password protection for areas or particular documents within your web site, large amounts of storage space, particularly if you wish to disseminate video data, and the ability to run interactive programs, if you wish to make use of certain types of online questionnaires and data collection.

When creating public web pages, you may wish to consider some of the aspects that allow pages to be successfully found via search engines, such as including your own keywords and all the relevant names if a theory, concept or object has alternative naming conventions. Similarly, you may use your own experience of what is pleasant to read and navigate when designing your layout or consult the growing range of books which attempt to explain good web page design to non-computer professionals.

Effective use of internet software
There are two main problems which may affect a useful internet work session. The first is poor design or broken technology on the remote web site or resource, the second is inefficient use of web browser software.

Frequently, there is little a user can do about remote web site failures or errors, frustrating as they might be. It is however, often worth sending the site administrator a short email pointing out the problem you have encountered. System administrators tend to be somewhat overburdened and are unable to spend vast amounts of time checking every nook and cranny of a complex web site to make sure it still works after every alteration. A polite email pointing out an error in the site is often useful for them, and may mean your required information is fixed within a matter of hours. On a less positive note, technically competent people (especially the overworked ones who are contacted out of the blue), tend to attribute problems to stupidity in the first instance and stop investigating a reported problem (rightly or wrongly) at the first sign that a user might not understand the technology. Less confident

users may wish to quickly check with a more experienced colleague that their problem is genuinely with the web site, and not their usage of the software, to increase the chances of a helpful response.

One alternative solution to missing or broken pages is to make use of internet search engines. If you click on a link which leads nowhere, or a web address you have been given does not work, try typing the title of the page into a search engine. If the page has moved, the search engine may have catalogued its new location. Another useful feature, pioneered by the search engine Google (www.google.com) is a system which stores copies of all the pages it knows about. Even if a page has been deleted from its original location, Google may still have a copy in its cache. Simply search for the page as normal, and click the 'Cached' link to see the saved version. A web site called the Way Back Machine (www.archive.org), solely exists for this purpose and has archives of web pages stretching back some years. It is also worth remembering that such archives are kept by third parties if you are considering putting personal or sensitive information on the web. You may be able to remove your own web pages, but will not be able to remove the same information from external archives.

The problem of inefficient web browser use can greatly effect the speed and ease of an internet work session. In the early days of the web, browsers were fairly small and lightweight. They had only limited functionality as web sites were relatively unsophisticated. More recently, due to the demands of newer web site technology, increased multimedia usage and (it has to be said) poor design, browsers have obtained a reputation for being slow, buggy and monolithic. Whilst this situation is gradually improving, a good grasp of how to maximise browser performance may save you a great deal of time and hair-loss.

There are some good practices that apply to almost all computer software you will use. Firstly, it is important to get a good overview of the software, a good habit is to read through all the main menus and familiarise yourself with the options before you start using any new piece of software. This will give you an instant overview of the package's functionality, and will also make any additional documentation (like the electronic help files) much more cognisant. Secondly, try and load or enable only the software, features or options that you need. If you feel competent in software configuration, experiment and see which options improve your usage. Often there are many like minded users on the internet, some of which kindly publish their gems of wisdom. A web search using the name of your software package and the word 'optimisation' (or 'optimization' to retrieve pages using the American spelling) as key words will often give you a wealth of information.

An excellent review article by Al-Shahu et al (2002) has lots of useful pointers in this regard, and the table below (table 1) is derived from their paper.

Table 1 Enhance your use of a browser

Maintain software
- Use the latest version of your browser (determine which version you are using under the "Help" menu, "About" in Windows, or Apple menu 'About' on the Macintosh)
- Check for new browser software monthly for the latest security patches.
- Use the latest versions of free software to view multimedia content (e.g.)
  Adobe Acrobat Reader (www.adobe.com/products/acrobat)
  Shockwave (www.macromedia.com/shockwave)
  QuickTime (www.quicktime.com)
  RealPlayer (www.real.com)
- Install virus protection software and keep it up to date (www.symantec.com, www.nai.com, www.zonelabs.com)

Shorten the time you spend on line
- For downloading large amounts of data, use the internet before global use rises (between midnight and noon in Europe).
- If available, use mirror sites (exact copies of web sites) located in, or close to, your own country.
- If the web site allows it, select text-only or low bandwidth options and omit multimedia content if the bandwidth of your connection is low.
- If network response is sluggish, open pages in their own windows (for relevant menu, right click in Windows, click and hold on the Macintosh) and continue working or browsing other pages, and return to them in a few minutes

Minimise memory use
- Choose to install only the components of the browser that are essential to you (a full installation can consume many megabytes of disk space)
- Close down browser windows and applications you are no longer using.
- Optimise the size of your cache or "Temporary Internet Files" folder.

Customise your browser
- Set your browser's home page to a blank page (about:blank) or the web site you use the most.
- Organise your "Favorites" or "Bookmarks" into folders.
- Set your preferred font type and size (under "Text Size" on the "View" menu)
- Maximise the viewable area in your browser by removing the explorer bar and customising toolbars to show only the functions you use (as small icons).
- Use the appropriate default programs for sending email, etc, from your browser.

Take short cuts
- When typing web addresses, omit "http://", as your browser will automatically append it.
- Use copy and paste functions to transfer web addresses between documents and browser.
- Right click (Windows) or click and hold (Macintosh) with your mouse to save images, sounds, or videos from a web site to your hard drive.
- If a web site cannot be found with the web address you have entered use a search engine to see if it available at an alternative location.
- Learn the shortcut keys that allow you to directly type in a web address without having to click on the location bar.

Ethics of Internet Communication

The use of internet communication by clinical neuropsychologists causes some novel ethical dilemmas because of two major considerations. The first is the privacy implications of using the internet and internet software (notorious for their lack of adequate security) for information which you may be legally and ethically bound to keep confidential. The second, is the issue of copyright and its use to restrict the dissemination of information which could aid the treatment of patients or education of clinicians, when such dissemination can be conducted for near zero cost when conducted via the internet.

Internet Security and Confidentiality

The idea that a patient's medical information should only be available to people directly involved in their medical care, and that it is the carers responsibility to maintain this confidentiality, are core values in the health care system. It will perhaps come as a surprise to many clinicians that sending information over the internet is as confidential as discussing a patient's details on a crowded bus. It may be true that no-one is interested but that does not change the fact that the information is available to many people to whom the patient has not consented access.

With easily available software, any person can intercept and store all of the unencrypted information on your local network without being detected. Government agencies routinely intercept internet traffic, and while this may not be considered a major concern for the majority of patients, it must be noted that in the recent case of General Augusto Pinochet's extradition from the UK, the decision rested on a neuropsychology assessment of his mental fitness. Whilst not all such ethical dilemmas might be as dramatic, each patient should be able to rely on the confidentiality of their clinical records or related information, including when they are communicated via the internet.

Similarly, much common internet software is susceptible to viruses which can also breach such confidentiality agreements. In the case of one particular virus which exploits vulnerabilities in popular email software, a document is randomly selected and mailed to everyone in the user's address book. This author has personally received a confidential case report which got mailed by this virus to a *public mailing list* which happened to be listed in the infected user's email address book.

One way of assuming responsibility for clinical confidentiality is to ensure that adequate advice is taken on the implications of using particular software and taking precautions to prevent unhappy accidents, such as running up-to-date anti-virus software. In the case of internet communication the use of encryption software to scramble the contents of messages so only the intended recipient can decrypt or unscramble the potentially sensitive information is currently the best method to ensure private communication.

The use of encryption software is, unfortunately, still scarcely used, and not as user friendly as it could be. However, this is rapidly changing, and is becoming accessible to motivated individuals willing to spend a little time learning the ropes. Any clinical neuropsychologists who are provided with their internet access by an employer or institution should push for encryption to be common practice rather than the exception and take good advice from competent computer professionals on suitable software for this purpose.

Electronic Publishing
The debate over the ownership of scientific literature has recently become particularly salient (see Laporte and Hibbitts, 1996, for an excellent analysis), largely because the traditional role of publishers as the cog wheels of journal distribution is becoming increasingly redundant as the internet becomes the preferred method for information dissemination. Since information can be distributed across the internet for near zero cost, questions have been raised about the ethics of using copyright to restrict information which could be used for the benefit of the patient and society at large (Bachrach et al, 1998).

However, whilst no-one would doubt the benefits of peer review in scientific and clinical research, doubts have been raised about the possible decline in quality that may occur if copyright for clinical and scientific journals is abolished (Bloom, 1998).

Clinical neuropsychologists may also face similar dilemmas when producing standardised neuropsychological tests. The question of whether it is ethical to cede copyright to a publisher who may charge large sums of money for a copy of a potentially beneficial clinical test is a thorny issue. For some tests (such as the Block Design subscale of the Wechsler Adult Intelligence Scale) that may require specifically prepared materials that cannot be simply provided as digital templates, it would seem that a third party publisher may be the best method of effective distribution. Many neuropsychological tests are however, produced by publically funded neuropsychologists and can easily be distributed as digital copies to appropriate recipients. Many would argue that to restrict and charge for clinical tests that may be used directly in a patient's care, or in valuable clinical research when a near zero cost distribution method is available, could be considered as unethical, or at the very least, obstructive.

Internet Resources
A static list of internet resources is likely to become increasingly obsolete as time goes on. However, these have been chosen as useful and reliable resources and may provide a starting point for the creation of your own internet resource list.

General Internet Resources

Google.
The most popular and arguably the best general internet search engine
http://www.google.com

Google Groups.
Allows web based access to usenet, an internet-wide discussion group system.
http://groups.google.com

Yahoo Groups
Email discussion list hosting site, that has established email discussion lists and allows creation of custom lists for free.
http://groups.yahoo.com

Netiquette and Good Internet Practice Guidelines.
http://www.faqs.org/rfcs/rfc1855.html

Online Dictionary
http://www.dict.org

WhatIs
Searchable online dictionary of internet and computing terms and abbreviations
http://www.whatis.com

Wikipedia
An online, collaborative encyclopaedia that has open content which can be used, copied and distributed without restriction.
http://en.wikipedia.org

Way Back Machine
A extensive archive of the world wide web, stretching back some years. Allows you to type in a web address and shows you previous versions, archived from the web.
http://www.archive.org

General Neuropsychology Resources

Neuropsychology.co.uk
Excellent, frequently updated site, with links to conference and neuroscience specific search tools.
http://www.neuropsychology.co.uk

PsychCrawler
Psychology specific internet search engine.
http://www.psychcrawler.com/

NeuroGuide
Neuroscience specific search engine.
http://www.neuroguide.com/

The Whole Brain Atlas
Comprehensive atlas of neuroimaged human brain structures, showing both normal structure and neuropathology. Has extensive interactive features to aid navigation and study.
http://www.med.harvard.edu/AANLIB/home.html

Sites to Support Evidence Based Healthcare and Research.

PubMed
Free web based access to the Medline Literature Database.
http://www.ncbi.nlm.nih.gov/PubMed/

CliniWeb
An index and table of contents to clinical information on the World Wide Web
http://www.ohsu.edu/cliniweb/

OMNI
Free access to a searchable catalogue of health and medicine internet sites.
http://omni.ac.uk/

BioMail
Free journal contents alerting service that allows custom searches to be regularly conducted on the PubMed database, and the results emailed directly to you.
http://www.biomail.org

Psycline
A guide to psychology and social science journals on the web
http://www.psycline.org

Highwire Press
Archive of full text journals that provide unrestricted free access.
http://highwire.stanford.edu/

Free Medical Journals
Archive of full text clinical and medical journals that provide free unrestricted access.
http://www.freemedicaljournals.com/

Free Books for Doctors
Archive of free, downloadable clinical text books on many subjects.
http://www.freebooks4doctors.com/

Associations and Societies on the Web

Headway
Web site of head injury support organisation providing information and support for head injury patients, their friends and family.
http://www.headway.org.uk/

British Neuropsychological Society
http://www.hop.man.ac.uk/bns

British Psychological Society
http://www.bps.org.uk

British Neuropsychiatry Association
http://www.bnpa.fsnet.co.uk

National Academy of Neuropsychology
Has plenty of professional information including online training materials, news and updated list of neuropsychology email discussion lists.
http://nanonline.org/

National Institute of Neurological Disorders and Stroke (NINDS)
American web site which has comprehensive resources on brain disease and pathology as well as regularly updated relevant news and contacts sections.
http://www.ninds.nih.gov/

Public Library of Science
Organisation aiming to make scientific literature and journal articles freely available over the internet.
http://www.publiclibraryofscience.org/

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