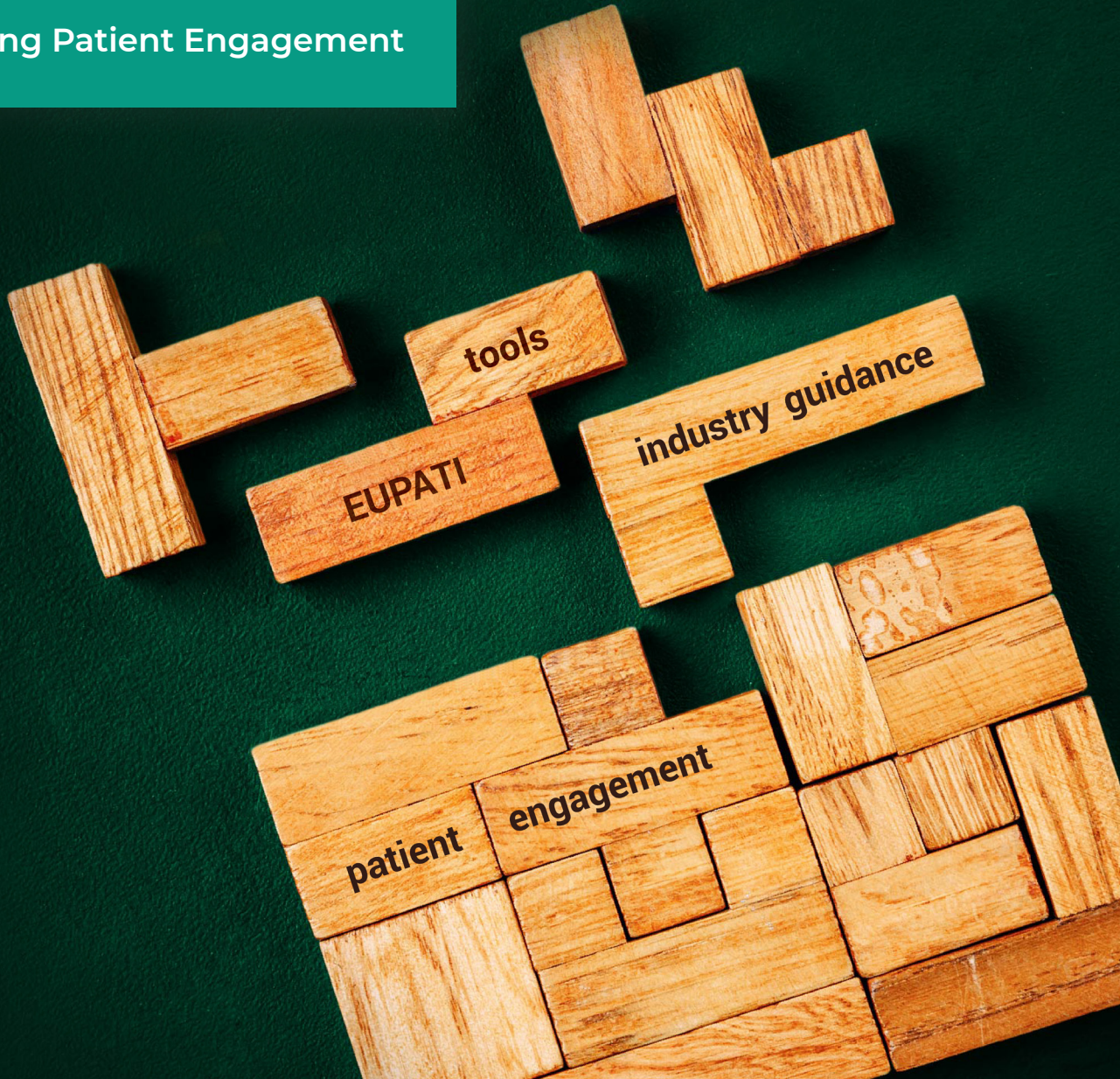




Planning Patient Engagement



Enhancement EUPATI industry guidance: Events and hospitality checklist

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What is this tool?

This checklist has been designed as a practical tool which may be used during pre-engagement planning of patient engagement activities and is designed to help individuals responsible for coordinating patient engagement activities consider specific patient needs for travel, meeting venues, accommodation and associated elements. For example individuals in a patient engagement role, groups directly organising the activity; legal and other support functions should be aware of these recommendations.

The checklist is written for general application across all different scenarios and aims to be simple to follow by all stakeholders involved. It defines high level considerations for events and hospitality and is not intended to be an exhaustive list.

Best practice is to have basic knowledge of the disease, typical symptoms and then apply as appropriate for the patients being engaged and their associated needs.

It is important to note that patient engagement does not only occur within the area of a specific disease; there will be interest in obtaining patient input/collaboration in areas not specifically linked to a disease. Therefore the checklist should be considered for all interactions.

This tool is complemented by one other document:

- Enhancement EUPATI industry guidance: events and hospitality¹

¹ Enhancement EUPATI industry guidance: suggested working practices, <http://imi-paradigm.eu/PEToolbox/enhanced-eupati-guide>

Events and hospitality checklist

This checklist has been designed as a practical tool which may be used during pre- engagement planning of patient engagement activities. It defines high level considerations for events and hospitality and is not intended to be an exhaustive list. Best practice is to have basic knowledge of the disease, typical symptoms and then apply as appropriate for the patients being engaged and their associated needs.

Considerations	Comments
Travel	
<p>Identify in advance the patient’s travel preferences, plus understand (and if possible) support the provisions patients may need to make at home to allow them to participate (i.e., childcare, eldercare)..</p> <p>For example, they may prefer train travel to flights. Try to achieve these where possible. Consider patient journey from start to finish. Identify all points of the activity requiring transport:</p>	
<p>Think about travel from the patient’s home to the airport/ station and return journey home</p>	
<p>Avoid long transfer times and instances where heavy traffic is likely. Arrange assistance and adapted vehicles for meet-and-greet service at meeting destination and airport or train station if required. Arrange for similar transport to restaurants if required.</p>	
<p>Can early starts be avoided by travelling the day before an activity? Many patients have a morning routine to manage their disease. Check what the patient’s needs are to enable optimal participation in the meeting.</p>	
<p>Make sure you agree on arrival and departure times with the patients, allow ample time between arrival time and activity start time in case there are delays.</p>	
<p>Arrange for patients to be dropped by taxi (or suitable transportation) as close to the venue entrance as possible.</p>	

Considerations	Comments
<p>Patients may wish to drive themselves, in these cases remember to reserve appropriate car parking close enough to the entrance of the venue.</p>	
<p>Support the patient when arranging their travel so that the extra luggage allowance in the cabin and the hold and special allowance for taking medication/oxygen, wheelchair etc. on the plane is organised with the airline beforehand.</p>	
<p>Remind patients to bring necessary medication, replacement oxygen cylinders, etc., with them. Inform the patient on what they need to bring as extra documentation (medication overview such as list of treatments, allergies, medicine passport, health records, letter from dietician and doctor on what is necessary like extra fluids/special foods/oxygen/needles or other devices (like implants, insulin pumps) etc). Identification may also be required by meeting venues, and at hotels.</p> <p>Remind patients to pack essential medicines and equipment (to the extent possible) in their hand luggage to avoid difficulties due to loss of luggage.</p>	
Companions/supporters	Comments
Considerations	Comments
<p>To facilitate and encourage patient involvement, allowing a patient to be accompanied by an adult supporter (carer, family member, friend, member of a patient organisation) even if not for health reasons is really important.</p> <p>Some people may be intimidated by the travel itself (particularly international travel), being in another country, with unknown people, in a completely different environment or need support at the meeting.</p> <p>If this is the case, the cost of travelling and accommodation, etc., of the supporter should be covered. It is easier for the patient/carer if bookings are made under one reservation: this may guarantee adjacent seating or enable changes to the booking.</p>	

Considerations	Comments
<p>In some cases, the supporter may be required before and/or during the meeting. If the latter, the supporter should be able to receive pre-readings and have a seat at the meeting next to the patient. If a supporter is needed, this person is expected to be able to provide the support needed and it should be made clear what is expected from them.</p>	
Accompanying minors	
Considerations	Comments
<p>For rules on accompanying minors, before arranging travel please check EU Reference document or legal regulations within the country the child is travelling both to and from. Each country has their own rules and individual insurance and permission from the other parent may be required.</p>	
Travel time	
Considerations	Comments
<p>Remember that travelling is tiring so providing support and adequate facilities is important. Depending on meeting duration be flexible, give patients the option to travel the day before the meeting and leave the day after the meeting. For example, if meeting start means the patient is expected to travel earlier than 07:00 and meeting end means the patient is likely to arrive home later than 22:00. Treat on a case by case basis, but ensure compliance with guiding principles.</p> <p>Think about the proximity of the venue closer to, or central to, where patients are generally located bearing in mind to keep their journey times manageable.</p>	
<p>Any meeting organiser should arrange and pay for travel and hospitality for patients and carers in advance to avoid patient(s) needing to pay in advance and then request reimbursement. (In order for payments to reflect fair market value, as an example for the U.S reference can be made to https://nationalhealthcouncil.org/tools-to-support-sponsor-patient-engagement-fair-market-value-calculator-and-engagement-templates/ and for UK to</p>	

Considerations	Comments
https://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/	
Accessibility	
Considerations	Comments
<p>Understand what special accessibility requirements are required. Don't forget toilet facilities sufficient for the number of patients expected to use them.</p> <p>Ensure transport provider (airline/airport/railway station) is advised of special assistance requirements and this is organised at the time of booking. For example, some airlines have seating for patients with Inflammatory Bowel Disease (IBD) or a meet and greet service for people with reduced mobility or disability, which may include provision of wheelchair (where needed).</p>	
Technical	
Considerations	Comments
<p>For virtual interaction, in advance of the activity check that technical equipment (hardware, software and infrastructure) you intend to use is accessible to patients and any potential barriers to participation. Where possible, provide support through a facilitator for testing, setup and troubleshooting. Consider the following:</p>	
Is internet in their area strong enough to support a virtual conference?	
Do they have a plan that allows for anticipated data usage?	
Will they be the only participant without a camera on?	
Do they have access to a suitable computer to enable them to view slides or other documents shared by presenter on screen?	
If running meetings where some people are attending in-person and others are attending virtually, ensure equity in ability to contribute.	

Hotel accommodation	
Considerations	Comments
Where applicable and possible, try to ensure availability of accessible accommodation for individuals with mobility restrictions or cognitive impairment considering the following requirements:	
Additional hostess assistance (shown to their room, wheelchair navigation, etc.).	
Bedrooms that are within close proximity to meeting space and/or near elevators to promote independence by aiding spatial orientation (check for preferences before booking).	
Wider door access with low spy holes, low-level wardrobe rails, and furniture. Avoid steps in room.	
Low-mounted (or remote control), comfort-control panel, and light switches (ideally with dimmable lighting) at bedside.	
Minimalist furniture, wall art, and coverings; wooden or laminated flooring; easy-pull blinds (rather than curtains); contrasting colours such as light switch next to doors (where possible).	
No transparent glass walls, such as those leading to bathroom.	
Telephone easily accessible (by bedside).	
Soft furnishings that can be changeable (such as pillows). Be aware of items that may trigger atmospheric allergies (dust, pillows, carpets, etc).	
Option to have adjoining room for carers.	
Option to have a fridge/freezer in the room to keep medication cool and/or option for ice to be available for medical treatments.	
Where possible, rooms should have temperature control panels, if this cannot be provided then heaters/fans should be available.	

Considerations	Comments
Facilities for service animals to accompany patient.	
Bed and mirror height suitable for wheelchair users.	
Seating (chair) available in the hotel room.	
Wider bathroom door access and wheelchair-friendly shower with fold down seat.	
Easy-to-use shower mechanics.	
Grab rails on both sides of a higher-level toilet, shower and bath. An emergency pull cord in bathroom linked directly to the Guest Services desk, which must be manned 24/7.	
Low-mounted towel storage and shelving as well as soap and other amenities. Ensure soap and amenities can be easily opened and ideally contrasted with sink (not white on white).	
Meeting venues	
Considerations	Comments
Walk the route patients will take, are there elevators available where needed? Complete this with people living with the condition where possible. Plan an alternative route if patients have limited mobility to avoid too much walking or stairs.	
Are the toilets clearly signposted, in easy reach and wheelchair accessible?	
Are you familiar with the fire evacuation and emergency procedures (and are these made available for participants)?	
Consider onsite medical assistance to be available (or where to go in case medical assistance is needed).	
Provide easy access and plenty of space around tables and chairs in the meeting room and catering areas. All meeting space / breakouts on one floor in a quiet/secluded area (for privacy reasons), if possible.	

Considerations	Comments
<p>Designated reserved seating for people with limited mobility or cognitive impairment should be available during large events.</p> <p>Table height should enable wheelchair users to be seated alongside other participants.</p>	
<p>Consider event registration of carer.</p>	
<p>You may need additional facilities such as fridges (for medication), provision for guide dogs, etc.</p>	
<p>Check if your venue requires a risk assessment.</p>	
<p>Choose a meeting venue with natural daylight if possible.</p>	
<p>If you are video recording your activity, consent from the participants should be obtained well in advance.</p> <p>Cameras require extra space and should not be intrusive, use of this equipment may make patients uneasy and nervous; always put patients at ease.</p>	
<p>Ensure all attendees are included in all activities (so as not to discriminate); for example, if a group photograph is required on the stage, ensure ramps are available.</p> <p>Remember consent for photographs.</p>	
<p>Other senses can be heightened, so keep noise to a minimum and avoid bright lights.</p>	
<p>Provide an additional meeting room / quiet room so patients can take medicine / time out.</p>	
<p>Provide tissues in the room if emotional topics are to be discussed.</p>	
<p>Rooms should have temperature control panels. If this cannot be provided then heaters/fans should be available. Check patients are comfortable.</p>	

Meet and greet	
Considerations	Comments
<p>Make sure someone is assigned to meet and greet the patient and companions on arrival at the meeting venue and ensure departure process is smooth. Exchange mobile numbers for ease of contact on the day between the patient and the host.</p> <p>Build in time for patients to settle, receive refreshments, meet hosts and others plus for receiving any final briefing or clarification, if they are willing so – otherwise allow them to take their time until the meeting starts. Make sure the patient is comfortable before the activity starts.</p>	
Catering / Dietary Requirements	
Considerations	Comments
<p>Hospitality is essential. Never underestimate the importance of hospitality, whether in the meeting venue or hotel bedroom. Tea and cakes/cookies/vegetable sticks/fruit are a small cost but provide great benefit.</p>	
<p>Understand the patient’s dietary requirements and make these available for the patient also in the small snack selection.</p>	
<p>Make sure water and other refreshments are available throughout the meeting. If, for example, people with dementia are at the meeting, remind them/encourage them to drink, hydration is very important.</p>	
<p>Consider (disease-specific) dietary requirements i.e. Paleo/vegan, remember certain food types can severely affect medicines.</p>	
<p>Consider certain patients have a heightened sense of smell, so try and keep very strong-smelling foods to a minimum.</p>	
<p>Ensure accurate and large font food labelling to allow for allergies and avoidance of food cross-contamination.</p>	
<p>Allow adequate time for comfort breaks and meals.</p>	

Considerations	Comments
Avoid working lunches/coffee breaks if possible (lunch is a break).	
Ensure social inclusion by providing sufficient seating in the meal areas for people who cannot, or do not wish to, stand and eat.	
If the venue/ hotel is not in a central location provide information about restaurants near the venue / hotel where the person stays and their accessibility.	
For meals outside the scheduled meeting, consider providing meal vouchers with a set monetary value or authorise meals to be charged to the room and paid by the meeting organizer, rather than expecting patient to request reimbursement.	
If off-site meals have been arranged (for example, an evening dinner) and a patient doesn't want to attend, respect their wishes and ensure their meals will still be reimbursed.	
Communication	
Considerations	Comments
Communication is essential, make sure to ask patients about their preferences for methods of communication and do not make assumptions about them. If possible, provide the phone number of a person who could provide support or clarify any issue to the person before, during or after the event if necessary.	
Send detailed pre-meeting information, including any pre-reads, slides, agenda, and information about the venue and how to get there (maps, useful info).	
Some people may prefer to receive the documents electronically and others as printed materials (ask the person about his/her preference).	
Consider alternative registration process (telephone, email, etc). Possibly communicate with carer rather than patient.	

Considerations	Comments
<p>Be discreet – i.e. use closed discussion between event planner and some high-need patients.</p>	
<p>Use blind copy option when communicating to groups via email so you do not share email addresses without the patients’ consent (either within group of patients or within your organisation).</p>	
<p>If a patient is asked to give a presentation, find out in advance what they require on stage. Consider: Do they need a lectern to hold their notes? Would an autocue be helpful? Comfort screen to see slides to front? Would they like someone else to move the slides on for them? Would they prefer a handheld, lapel microphone or headset?</p>	
<p>Materials developed for use during patient engagement activities should use lay language and participants from industry or academia may need to adapt the language they use to communicate and describe scientific and medical topics clearly.</p> <p>Use short and clear sentences and avoid use of jargon and acronyms (if these are necessary, include a glossary of terms). Consider larger font size on printed materials and clear layout (e.g. colour contrast, line space/ white space, bullet points).</p>	
<p>Make sure everyone feels comfortable and has opportunities to speak. Remember that some people may not be speaking in their mother tongue (provide “extra time” for them and ensure facilitators/ chair/ presenters do not speak too fast).</p>	
<p>If required, provide an interpreter and allow extra time for instantaneous translation during interactions.</p>	
<p>Are there other tools required to enable communication and provide appropriate time/opportunities for meaningful participation?</p>	